Close Encounters of the Genetic Testing Kind:

Negotiating the interfaces between Matauranga Māori and other knowledge systems

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I dedicate this thesis to the one man in my life '**DONALD TAUPO**'
(11 August 1954 – 11 January 1999) my dad who showed me the value of unconditional love, patience, compassion and tolerance towards others…
Your light was extinguished before I knew my potential
And before I could share some of the joys of my life with you
And so now
Dad
All I want to say to you is
Thank you for being my inspiration in life and my security in death.
Love you're big girl
Trina

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Abstract

Since the decoding of the human genome project concluded in 2003, rapid technological advances in the area of human genetics including genetic testing and bio banking have accelerated. Public discussion of genetic testing and biobanking are the focus of this thesis. Genetic profiling and predictive tests aim to establish the causal conditions for disorders such as Fragile X, cystic fibrosis and Huntington's disease. Biobanking involves the storage of genetic material for genetic research and can also include genealogical research.

The complex and varied relationships that Māori (indigenous peoples of New Zealand) in different social locations have with western science (and human genetics in particular) is at the heart of this thesis. The thesis explores the responses of three differently located Māori social groups to the challenges posed by genetic testing and biobanking. Focus/contact group discussion with Māori members of the Church of Jesus Christ of Latter Day Saints, a group of rongoa or traditional Māori health practitioners, and a group of Māori lawyers illustrate both diversity in the ways in which Māori respond to the issues posed by human genetics, and connections among them as they draw on Māori ontologies and epistemologies. In the analyses of these discussions which constitute the core of this thesis, Māori can be seen juggling alternative frames of reference and negotiating between knowledge systems.

The thesis does not purport to provide an overview of Māori responses to genetic testing. Instead it uses discussion among three groups of research participants to illustrate the relevance of temporal and relational knowledge in local situations. A range of social science and Te Ao Māori conceptual tools are used to analyse conversations among research participants. These tools include discussion of power/knowledge and governmentality, actor network theory, sociological discussions of agency as well as concepts of whakapapa, kaitiaki, mauri, and mana motuhake. My goal is to illustrate both connection and heterogeneity in Māori responses to the challenges posed by genetic testing and bio banking.

Nga Kupu / Glossary

Atua	Supernatural Beings
Aotearoa	Literal translation "Land of the Long White Cloud"
Hapu	Sub-tribe
Haka	Rhythmical dance, Traditional War Challenge
Hineahuone	First Woman made from Earth
Hinengaro	intellect, conscience, heart
Hongi	Salute by pressing noses together
Iwi	Tribal people defined geographically
Ira	Gene
Kaha	Strength
Kaitiaki	Guardian/stewardship/responsibility
Karakia	Incantations/Prayer/Rituals
Kaumatua	Elders
Kaupapa	Rules/Norms
Kawa	Protocols/Procedures
Kawai Tipuna	Deity/Revered Ancestors
Kawanatanga	Government
Kete	Basket
Koha	Donation, Gift, Parting Message
Kumara	Sweet Poatato
Makutu	Incarnation/Spell/Curse
Mana Motuhake	Power of Authority/Agency/Influence Fundamentally, mana is about prestige, power and status. The principle is also intertwined with Mana Atua, Mana Tipuna, Mana Whenua, Mana Tangata, the power of the Kawai Tipuna, the power of the Ancestors, power of land and of the individual (Moeke-Pickering, T. (1996).
Manaaki	Show respect/kindness
Manaakitanga	The act of manaaki/hospitality
Māori	common/ordinary – Indigenous Peoples of New Zealand
Marae	Meeting Place
Makutu	Traditional Māori curse
Matakite	Visionary,
Matauranga Māori	Traditional Māori Knowledge
Matauranga momo whakaheke	Knowledge of inherited characteristics

Mauri	Life principle/force/essence
Mihi	Greeting/Introduction
Mokopuna	Grandchild/Grandchildren/Descendant
Moteatea	laments, selection of tribal songs
Nga Taonga Tuku Iho	Treasures passed down from the Gods
Pakeke	Adult
Papatuanuku/Papa	Earth Mother
Purakau	story
Patere	Rhythmical chant, flow
Poroporoaki	Farewell
Powhiri	Welcoming Ceremony
Rakau	Tree, Wood
Ranginui/Rangi	Sky Father
Rangatira	Chief
Rangatiratanga	Principality, sovereignty
Rongoa	Traditional Healing, Health Remedies
Tanemahuta/Tane	Deity of the realm of the Forests/flora and fauna
Tangaroa	Deity of the realm of the Oceans/waters
Tangata Whenua	People of the Land
Taonga	Treasure/Gift
Tapu	Laws/ Guidlines
Te Ao Marama	World of life and light
Te Ao Māori	World of Māori
Te Kore	The Beginning of the World, nothingness
Tikanga	Values/customs
Tika	Authentic, true
Tinana	Body
Tino Rangatiratanga	Autonomy/Self determination/sovereignty
Tipuna	Ancestor/s
Tohunga	Skilled/Expert/Knowledgeable
Waka	Kingship group, boat or canoe
Wananga	
Waiata	Song
Wairua	Spirit
Whaea	Mother/Aunty/Adult Woman
Whaikorero	Make an Oration, Speech
Whakapapa	Genealogical Descent of tangible and intangible
Whakairo	Carving
Whakatauki	Proverbs/Sayings
Whanau	Family/Descent Group/to give birth

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CHAPTER 1
Deconstructing Genetic Testing

Terms: Biotechnology, commensurable, epistemology, genetic engineering, genetic testing, incommensurable, kaitiaki knowledgeability, ontology, paradigm, sociality and whakapapa are discussed in Appendix I.

1. Science and Culture - Dismantling Dichotomies

In 2003 a leading paediatric geneticist in New Zealand, Dr Stephen Robertson began to investigate a rare genetic disorder that had contributed to the death of seven male babies in one Māori whanau (family) (Meduna, 2005; Child Health Research Foundation, 2003). Genetic tests carried out on the mothers of these babies identified 'localised mutations in the FLNA gene' (Robertson et al., 2003). These gender-linked X-linked mutations were the source of the severe birth abnormalities.

This scientific discovery challenged the beliefs of some whanau members who thought that the whanau were recipients of makutu (traditional Māori curse). Their understanding of makutu as the source of these birth defects draws on Māori epistemologies (ways of justifying knowledge claims) and ontologies (conceptualisations of what exists). These traditional understandings have their origins in Te Ao Māori (Māori worldview) and integrate material and spiritual realms (Henare, 2004, Clarke, 2004). Practices associated with advanced health biotechnologies in the 21st century, namely genetic testing, have provided this whanau with a scientific explanation for the deaths of these children - an alternative explanation to the cultural understandings that informed the conclusion that makutu was the reason for the deaths of these malformed baby boys.

Two worlds, Māori and non-Māori and the intricate complexities within them provide the context for different understandings of birth defects in this family, and have the potential to alter understandings of what this whanau means to itself, and to others. The interactions between this geneticist and this Māori whanau also disrupt stereotypical assumptions about scientists in general and geneticists in particular. Often scientists are seen as operating in isolation from social, cultural and environmental contexts (Cobern and Loving 1998). As a result, many Māori

are suspicious about science and sceptical about what scientists might offer their communities (Tuhiwai-Smith, 1999a, 1999b; Pihama, & Phillip-Barbara, 2000; Bishop, 1996; Cunningham, 2000). However, as a geneticist interested in solving the mysteries posed by these repeated birth defects, Robertson did not only work in his laboratory. He also developed an intense social relationship with this whanau which crossed ethical, social, political and cultural divides (Meduna, 2005). At the same time, this interaction between a geneticist and a particular Māori whanau highlights some of the disparate worldviews and perspectives at play in contemporary New Zealand, as people address the implications of new genetic science. It illustrates the differences between scientific and traditional Māori ontologies, and also the ways in which scientists and Māori, whanau, hapu and iwi can develop cooperative, mutually respectful relationships. These relationships and understandings will need to be developed as legislators; policy analysts and diverse publics seek to develop regulatory arrangements and codes of practice relating to human genetics that give appropriate weight to Māori cultural perspectives, including traditional ontologies and epistemologies.

2. The Thesis Agenda

The complex and varied relationships which Māori in different social locations have with western science (and human genetics in particular) are at the heart of this thesis. The research explores the responses of three differently-located Māori social groups to the challenges posed by genetic testing and biobanking. Focus group discussion was arranged with Māori members of the Church of the Latter Day Saints, a group of rongoa (traditional Māori health practitioners), and a small group of Māori lawyers. These groups were selected based on my personal experiences and participation in the various fields of knowledge; religion, law and traditional medicine. Each group was recruited by members of the Te Kopere research team and therefore as the principal researcher I did not have any prior relationship. To this end an extended rationale outlining the recruitment of these three groups is provided in the research methodology chapter 3.

Discussions held with the three groups are used to illustrate diversity in the ways in which Māori respond to the issues posed by human genetics, as well as similarities in the ways they use Māori ontologies and epistemologies. In the reviews of these discussions, which constitute the core of this thesis, Māori can be seen juggling alternative frames of reference as a method of negotiating across knowledge systems.

These skilful negotiations between knowledge systems, and the encounter between Dr Stephen Robertson and a particular Māori whanau, stimulated my interest in Thomas Kuhn's (1962) discussion of 'shifting paradigms' in science. Kuhn's attention to the social and historical production of scientific knowledge and the relationships between incommensurable paradigms has informed my reflections on relationships between formal scientific knowledge and Matauranga Māori (Māori traditional knowledge systems). These connections are discussed more fully in the following chapter.

My interest in the ways in which different groups of social actors respond to issues associated with genetic testing was also stimulated by insights that Emirbayer and Mische have developed using Mead's concept of sociality (Emirbayer & Mische, 1998). Emirbayer and Mische define sociality as 'the situatedness of actors'. Furthermore, they define the ways in which actors produce or engage with knowledge as drawing on and requiring 'multiple temporal and relational contexts' (1998:969). In this regard, the participants in this study can be seen as what Emirbayer and Mische refer to as 'multiple actor-teams' that engage with genetic science across a range of discourses and shifting locations. I see the Māori participants in this study as multiply located with respect to the religious/spiritual, traditional Māori and legal knowledge they bring to discussion of human genetics.

The thesis uses interactive discussion among research participant responses on issues relating to genetic testing to illustrate the relevance of 'sociality' or situated temporal and relational knowledges. My goal is to analytically engage with both the connections and heterogeneity found in Māori responses to the new challenges posed by genetic science, and human genetic testing in particular.

3. Casing

At the core of the thesis is the research strategy which Ragin (1992:221) has referred to as 'casing' – the process of "matching ideas and evidence". This involves attention to information or empirical 'evidence' that is examined "through blinders that hide all but their theoretically relevant, general features" (Ragin, 1992:220). Out of a range of community group discussions within a larger research project,[1] I chose to focus on cases of discussion among Māori members

[1] This MA thesis research was conducted as part of a larger project - Constructive Conversations/ Korero Whakaaetanga: 'Biotechnologies, dialogue and informed decision-making' (CC/KW). This five year research

of the Church of the Latter Day Saints, rongoa practitioners and Māori lawyers. This process of 'finding' has been shaped by the theoretical and political agendas outlined in this introduction and in the following two chapters. Attention to these theories and political agendas has involved negotiating the complex relationship between sociological and Māori ontologies, epistemologies and associated research practices. The relationship between these ontologies has been the focus of the intellectual journey recorded in this thesis. This relationship mirrors the negotiations between ontologies and epistemologies which I identified in the 'cases' of discussion among Māori members of the Church of the Latter Day Saints, rongoa practitioners and Māori lawyers.

4. Constituting social positionality

The ability to use genetic tests to categorise the molecular patterns of DNA[2] which embody genetic blueprints enabled geneticists to identify and sometimes manipulate previously unidentified causal factors in human health. A report commissioned by the National Advisory Committee on Health and Disability (NHC, 2003b) considered the current practice of genetic testing in New Zealand and observed that genetic testing is widely used and rapidly advancing in New Zealand. The Committee concluded that the regulatory processes in place were inadequate and that there were insufficient resources for providing genetic testing services (National Advisory Committee on Health and Disability, 2003a, 2003b). As public awareness grows about the knowledges available through genetic tests, greater demands will be placed on health systems to provide such tests. Current international trends suggest that increasing demand results in more genetic tests being ordered by non-geneticists through laboratories. This contributes to the commercialisation of genetic material and technologies (Barrett & Hall: 2001).

All those affected in New Zealand by genetic policy and practice confront challenges as technological advances pose questions about what one might want to know about one's genes, why, and when you might want to know about your DNA. However, Māori confront particular challenges. Scientific and Māori worldviews present incommensurate approaches to questions

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project was funded by FRST, the Foundation for Research, Science and Technology in 2003. The first stage of this project focused on developing and implementing strategies for public discussion about the social, cultural, ethical and spiritual implications of genetic profiling of newborns, direct to consumer genetic testing and the storage of genetic information. This was part of a larger research agenda driected at exploring the implications of new health biotechnologies. See the project website: www.conversations.canterbury.ac.nz for information about the project and research reports. A core component of this stage of the project was attention to Māori definitions of issues associated with emerging health biotechnologies and the use of Māori conversational strategies in facilitating talk about these issues. The first round of focus groups associated with this study involved conducting twenty-five groups. Nine of these groups were groups were Māori groups. This thesis research focuses on conversation in three of these focus groups, all of which were facilitated by the author of this thesis and another member of the research team.

[2] DNA stands for deoxyribonucleic acid - our genetic blueprint

concerning genetic testing that are often in contention with Te Ao Māori (Māori philosophy or worldview) which has been seen as an inferior knowledge system to western science (Belich, 1996: 21; Wills, 2000). The new human genetics challenges Māori, in different social locations and with different forms of knowledge, to consider the social, cultural, ethical and spiritual implications of genetic science.

Whilst there has been limited academic literature concerning Māori positioning and response to genetic science, particularly human genetics, there have been reports commissioned by the New Zealand Royal Commission and the Bioethics Council to scope concerns and issues Māori might have generally to biotechnologies and to GMO's (Genetically Modified Organisms) (Satterfield et al, 2005; Reeves, 2004, Royal Commission, 2000 Cram et al 2000; HRC 1995). These reports suggest that Māori concerns are acknowledged, and at least partially engaged with, at state policy levels. A recent contribution to knowledge in this field is a report entitled 'Culture, Risk, and the Prospect of Genetically Modified Organisms as Viewed by Tāngata Whenua' (Satterfield, et al 2005) that presented new findings regarding Māori responses to GMO's (genetically modified organisms). This study, funded by the Foundation for Research, Science and Technology, includes the first large-scale qualitative study of the ways in which Māori community organisations, professionals, religious and political leaders respond to issues relating to the new genetics. This report offers an in-depth review of values and principles expressed across by a range of differently positioned Māori concerning genetically modified organisms. Satterfield et al focus on the field of genetic modification and attend to diversity in Māori response to GM. Similarly, I argue that there is no single Māori view. My aim is to illustrate diversity in the approaches of differently situated Māori participants in this study, but also to explore the ways in which each of these groups draw on overlapping sets of understandings or political commitments.

There has been little work done in Aotearoa New Zealand on the field of genetic testing on humans and the implications of this technology for people generally, and Māori in particular. These general challenges provide the backdrop for this thesis. I do not attempt to identify how Māori in general are responding to the social and ethical issues posed by genetic testing and biobanking. However, I do explore how three Māori groups, drawn from diverse social worlds, position themselves within some debates about genetics and human health. I am particularly interested in illustrating how some of the participants assert their mana motuhake (agency) in matters associated with the new genetics. To this end I focus on how members of the Church of Jesus Christ of the Latter-day saints (LDS or Mormon's), a group of Rongoa practitioners and a

group of Wellington lawyers talked about the relationship between their positioning as Māori and the challenges they considered were posed by genetic testing.

All three groups have similar understandings about the underlying values and principles of the Māori world that derive from the holistic knowledge system generally referred to by Māori as Matauranga Māori (traditional Māori knowledge base). According to this ontology, each individual is linked to a common ancestor defined by whakapapa (genealogical descent) which locates that individual in terms of their descent. Individuals are also connected to a waka (canoe), mountain, river, lake, ocean, marae (centre of collective engagement), whanau (familial collective), hapu (work collective) and iwi (political unit) of a particular region (Walker, 1989). These regional locations involve a mix of genealogy and geography that sets individuals, whanau, hapu and iwi apart from other individuals, whanau, hapu and iwi. In this regard, Māori are defined as necessarily diverse rather than homogeneous. This stands in sharp contrast with a dislocated universal individuality that is sometimes identified in discussions of bioethics (Scott, et al, 2005).

The research participants' commonality is based on their ethnicity as Māori, but their bodies, associations and identities derive from heterogeneous whanau, hapu and iwi traditionally sectioned into various regional bases or zones throughout New Zealand. At the same time, these groups vary between one another in their different fields of expertise in Mormon theology, rongoa (traditional Māori medicine) and the contemporary legal system. While recognising connections among these research participants, particularly with respect to their use of Māori conceptual tools, this thesis aims to disrupt notions of Māori homogeneity. It does this by asserting Māori heterogeneity through situating the research participants within their diverse social worlds and by demonstrating how these different locations shape participant responses to issues associated with genetic testing and biobanking.

A subsidiary theme of this thesis involves a critique of a range of essentialist/homogenising assumptions of 'otherness' which non-Māori have imposed on Māori. Such assumptions have been found in other colonial/indigenous situations and historical trajectories. The term Māori is itself problematic since the literal translation of the term means 'common' or 'ordinary' and is a term that colonialists adopted from the tangata whenua to refer to the tangata whenua generally (King, 2003:79; Ward, 1973:3). Moeke-Pickering contends that: "Māori identity was conceived of in an ecology devoid of contact with people who were not Māori" (1996:1-2). The iwi grouping is a later colonial construct that categorised whanau and hapu groups as wider tribal groups that were determined by their geographic location. Traditionally a fragmented people, the

indigenous peoples of New Zealand, through contact with British colonisers, began to be constituted as a collective and essentially 'othered' single group identity, distinct from non-Māori (Buck, 1977; Orbell, 1998; Barlow, 1991; Firth, 1972; Moeke-Pickering, 1996).

I will consider Māori heterogeneity when I look at how participants position and reposition themselves in various ways. This analysis looks at the multiple and shifting paradigms used by three sets of Māori participants in a larger study of the social, cultural, ethical and spiritual implications of genetic testing and biobanking. Together with other participants in this study, these groups responded to the possible implications for their everyday lives of newborn genetic profiling, 'direct to consumer' genetic testing and the storage of genetic material in biobanks. Kuhn's (1962) analysis of paradigm shifts in the history of science is used to explore the multiple and shifting paradigms which participants/actors use as they respond to the issues raised in focus group discussions about genetic testing and biobanking.

Locating the participants within diverse social relational networks requires a consideration of the concept of 'situated knowledge' (Haraway, 1991). Donna Haraway has explored the way in which knowledge is always social and situated. She argues that knowledge practices are constructed and selected according to social institutions and processes and consequently engaged in various ways with exploitation oppression and differential agency (ibid). In Chapters 4 to 6 I attempt to illustrate the ways in which participants' social location shapes their responses to issues associated with genetic testing. I will also demonstrate the similarities and differences between participants who are members of the Church of the Latter-day Saints, rongoa practitioners, and lawyers.

Against a backdrop of political and social uncertainty, the New Zealand Government is currently confronting the possibility of the normalisation of genetic testing as more tests become available and genetic medicine develops. Will it be appropriate to develop specific legal safeguards with respect to genetic testing and the storage of genetic information, or is current legislation adequate? How do differently positioned groups in the community define the social and cultural issues associated with genetic testing? Are there any concerns about the social, cultural and ethical and spiritual implications of this technology? What are the possible implications of the commercialisation of genetic testing in New Zealand? Do members of the public consider that genetic tests should be free and offered through the public health system? These issues are explored by considering in some detail the responses of the three very different focus groups to a

set of research materials developed as part of a larger study of the implications of genetic testing and biobanking.[3]

5. Exploring the Interface of Genetic Science and Māori Epistemology

This thesis explores the interface between Māori conceptual systems and contemporary genetic science. Mason Durie has discussed what he refers to as 'interface research' - research that utilises two sets of values and methods to produce gains for indigenous peoples including Māori. Most Māori, according to Mason Durie, live at this 'interface' (2004a). Interface research is an attempt to "utilise two sets of values and methods not simply to bridge the benefits…but to produce gains for indigenous peoples most of whom live at the interface" (2004a: 8). This thesis aims to exemplify interface research following Mason Durie's (2004a) approach. I attempt to explore the way in which the actors/participants in this study engage with the interface between Māori and other cosmologies. How do they mediate and represent their positioning with respect to genetic testing and as Māori, while differently positioned with respect to spiritual belief, expertise in traditional medicine and professional legal training?

My thesis challenges a contemporary tendency to consider Māori as a homogeneous people (Ward, 1973; Stokes, 1992). At the same time, I recognise that there are underlying customs and values that constitute a common miro (thread) that weaves throughout a traditional past and sets Māori as indigenous people of this place apart from other citizens of European, Asian, Pacific, American and African descent. As Durie indicates, custom is not static "… or at least the custom of native peoples, or that native custom ceases to exist when the people abandon grass skirts or no longer travel in dug out logs" (Durie, E: 1998). This thesis attempts to capture the dynamic components of culture that Durie has identified. It also explores how diversity as well as connection is evident in the responses of three different sets of Māori participants to issues relating to genetic testing.

Focus group interviews with Māori members of the Church of Jesus Christ of the Latter-day Saints (LDS) church suggested that Mormons grounded in gospel teachings moved sometimes with difficulty and sometimes with ease within Māori social and cultural worlds. The rongoa

[3] For discussion of the preliminary findings of the overall study within which this thesis research is located see 'The Social, Cultural, Ethical and Spiritual Implications of Genetic Testing – Preliminary Findings, Du Plessis, Scott, & Te Kopere team, 2004. This research report provides an overview of issues that arose in the focus group discussions. Also of relevance is 'Talking about Genetic Testing: Information for Participants', Participation Sub-team, 2004. This report was produced for research participants after the first round of focus groups and was used in follow up group interviews.

practitioners who participated in this study expressed ambivalence when it came to technology and science. They drew on critical understandings of a regional, historical colonial past in their responses to genetic testing issues. For the Māori lawyers who participated in this study, the Treaty of Waitangi continues to be crucial as a tool for negotiating relationships between people and the New Zealand state generally and is highly relevant when thinking about the specific challenges of human genetics. Their use of treaty discourse suggests a way in which Māori can participate in decision-making processes about genetic testing and 'find' a particular place, or range of places, in debates about the potential impacts of genetic technologies.

In the following section I provide a brief overview of genetic testing practices in New Zealand and highlight the specific aspects of genetic testing that will be considered in subsequent chapters.

6. Defining Genetic Testing in New Zealand

The rapid development of genetic testing has prompted interest in how this technology will be used and controlled in New Zealand. Genetic technology has been developed predominantly outside New Zealand and tests that have emerged inside New Zealand are likely to the outcome of research in laboratories (National Advisory Committee on Health and Disability, 2003b). Genetic testing is a complex process dependent on accurate interpretation of results. The tests vary in sensitivity and include prenatal genetic diagnosis, detection of mutations, predictive and/or susceptibility testing and presymptomatic testing that is used to assess future likelihood of development of genetic disorders (National Advisory Committee on Health and Disability (National Health Committee), 2003a). In the New Zealand context, genetic services are limited, but provide a comprehensive range of services including: "education and information, family history, domination and assessment, clinical assessment and diagnosis and patient management" (National Advisory Committee on Health and Disability (National Health Committee), 2003a: 15-16).

Testing for diseases such as Huntington's disease, Cystic Fibrosis and Fragile X involve analysis of an individual's DNA. Sometimes mutations may be found which involve extra, missing or rearranged chromosome material (Independent Biotechnology Advisory Council, 2002). The changes could also be extremely small, affecting just one or more of the chemical bases that make up DNA. Since it involves complex and highly sensitive processes, genetic testing is dependent on the skilled application of laboratory procedures, and on the accuracy of

interpretation. Processes vary in sensitivity. Results for detection of mutations, susceptibility to genetic disorders, predictive and diagnostic testing all vary in accuracy with results varying in sensitivity, for example, detection of mutations, susceptibility, predictive and diagnostic testing (Independent Biotechnology Advisory Council, 2002:7).

Genetic data bases or bio banks that store large quantities of genetic material are also part of the genetic testing phenomenon. Mannhalter, (2003) argues that "genetic data banks represent the means to identify the relations between genetic factors, lifestyle or environmental exposures with disease susceptibility and treatment response" (2003: 1). Generally, whole blood, dried blood, isolated cells, buccal cells and/or tissues are stored. While NZ Genetic Services personnel state that they are extremely careful about the ways in which information about people's DNA is currently stored,[4] there are concerns about the privacy of this data, particularly if tests are provided in a commercial environment. Whilst genetic testing may be beneficial for identifying potential problems and calculating population-wide risks, testing may not provide specific information about the particular effects of any type of genetic variation on any particular individuals.

The provision of new genetic tests, including genetic profiling, predictive testing and the storage of genetic data, prompted consideration of the benefits and limitations of genetics in the mid-1990s (Baird et al, 1995). The prospect of an increase in the availability and accessibility of genetic testing generates questions about how to provide and monitor services, and about what it means for individuals and communities to access information about their DNA and act upon that knowledge. As new tests are developed that are claimed to predict peoples' chances of developing chronic diseases, such as like heart disease and diabetes, health care professionals, academics and researchers are challenged to consider the social, ethical, cultural, and policy implications of new genetic technologies.

Petersen and Bunton suggest that: "The findings of genetic research are being rapidly applied in practices of population screening, diagnostic testing and counselling and promise to revolutionise the treatment of disease through the development of new therapies and drugs, profoundly affecting personal and social life" (Petersen & Bunton, 2002:1-2). The expansion of available genetic tests, including the potential impact of these health technologies on individuals, families and local communities, is an important social issue that has received limited academic

[4] See Scott, A. & Du Plessis, R. (2006) Redefining a Technology: Public and Private Genetic Testing in Aotearoa/New Zealand'. Paper under review.

attention within New Zealand. There has been even less consideration of genetic testing and its implications among Māori community groups and organisations. This thesis focuses on the ways in which diverse Māori community groups and organisations utilise a range of specific and shared knowledges as they discuss the possible implications of genetic testing and the storage of genetic data.

7. Genetic Testing as a Global Phenomenon

Whilst genetic services in New Zealand are usually carried out by publicly funded medical and research institutions, genetic testing is increasingly being provided by commercial companies. Currently, the 11th International Congress of Human Genetics is about to take centre stage at the Brisbane Convention and Exhibition Centre which will focus on draft policies concerning "DNA presymptomatic and predictive testing for genetic disorders" (see http://www.hgsa.com.au/main.html). Genetic testing in Europe is also under review and processes are in place for considering a network for test development of 'harmonization, validation and standardization of services' (see www.eurogentiest.org).

The Genovations and Familion corporations offer expensive predisposition and genetic profiling tests for clients interested in accessing information about potential genetic disorders (Barrett, S., & Hall, H: 2003). McKusick suggests that in the "past 25 years (1956-1991) human genetics has become 'medicalized, subspecialised, professionalised, molecularized, consumerized and commercialised'" (1992: 667). The implication of these trends for the utilisation of human genetics in Aotearoa New Zealand requires attention. There is a particular need to look at the implications for Māori, especially the ways in which different groups of Māori might participate in decision-making relating to the provision of genetic services in this country. This thesis contributes to this consideration of the implications of the expansion of human genetics in New Zealand by exploring the ways in which three sets of Māori talked about genetic testing and biobanking, including commercial issues.

Expansion in genomic science and the world-wide promotion of preventative biomedicines demonstrates the potential to radically transform conventional health care. The 'Genovations' website, for example, suggests comprehensive outcomes from genetic testing:

> Genovations™ is the advent of truly personalized healthcare.
>
> By harnessing the ingenuity of new breakthroughs in genomic science with the power of preventive biomedicine, Genovations™ offers an innovative, advanced health care model for more effectively preventing and treating chronic disease. Our predictive genomic profiles assess genetic variations in

each person that, when combined with modifiable factors in the environment, may increase disease risk. This empowers physicians and patients to realize:
• Earlier, more effective preventive interventions-years before disease develops
• Precise, customized therapies that truly address each individual's needs
• Improved clinical insight into patients with treatment-resistant "chronic" conditions

(Genovations, 2006)

There are a number of direct-to-consumer genetic tests such as the Genovations test currently being marketed internationally. Yap claims that "genetic testing conveys complex information that is of variable clinical utility and the direct-to-consumer market is likely to mis-communicate or even manipulate consumer behaviour" (2005:16). These issues were considered by the Māori research participants in this study.

8. Problematizing Genetic Testing

The practices of genetic testing and bio banking and their advocacy are situated within Eurocentric scientific discourse. Coburn & Loving (1998) argue that science as a specific system for generating knowledge developed in Europe during a period of expansion, exploration and conquest. This suggests that science was one of the tools used to modernise and supplant traditional indigenous knowledges and cultures. This historical pattern shapes current responses by indigenous people, especially Māori, to science and to human genetics in particular. These connections between science, processes of colonisation and the undermining of the status of Māori ontologies and epistemologies were clearly articulated by the rongoa practitioners who participated in this study (See Chapter 5). However, other research participants were also acutely aware of the links between science and colonisation and saw these issues as still pertinent in the 21st century. I think that it is useful to think of the knowledge system of medical genetics and Māori conceptual systems as incommensurable paradigms. These knowledge systems can be examined as equals or 'neighbours' on one hand, yet dissonant and incommensurable on the other. These issues will be discussed in more depth later in the thesis.

Donna Haraway (1991) asserts that science is characterised by reductionism, when "one language must be enforced as the standard for all the translations and conversions" (1987:4). Haraway argues that science invokes "world-changing persuasions that take the shape of the world into effective objects … like microbes (infective vectors), quarks (elementary particles) and genes (biomolecular codes)" (1987:2). In this regard, Haraway views science as being socially manufactured knowledge that asserts its objectivity. There is a tendency to

compartmentalise the human self from the scientist as knowledge producer. This stands in stark contrast to indigenous people's understanding of knowledge as always produced by people who are identified in terms of their social relationships to other people and to land, water, and other living and inanimate things.

For some Māori, the remnants of colonization are actively visible in the context of genetic science. The colonization process that gripped Māori in the 19th and 20th centuries saw the breakdown and near complete destruction of mana through the erosion of tapu, 'the all pervasive spiritual force that controlled Māori behaviour and underpinned the mana of chiefs' (Clarke et al, 2004, 51-58). Colonial ideas reflected the orthodox attitudes and belief systems of a British Empire that extended its imperial domination to indigenous peoples worldwide. Colonialism was associated with assimilationist policies and legislation that would dispossess Māori and leave them often landless and dependent on state support. Māori responses to contemporary science and genetics have been shaped by the individual and collective aspects of their critiques of their colonial experience. This will be illustrated in Chapters 4 to 6 which focus on the ways in which three groups of Māori spoke about genetic testing and biobanking. Māori responses to western science and genetics in particular, are also shaped by Matauranga Māori. The following section discusses Matauranga Māori in terms of its contrast, as a system of knowledge, with western science.

9. Matauranga Māori

While Māori experienced colonisation, the loss of land, the imposition of the English language, and the assertion of science as superior to Māori knowledge systems, Matauranga Māori (traditional Māori-based knowledge) was preserved during the colonising process and during the last 200 years. Currently, Matauranga Māori is being revived, re-interpreted and re-presented in written form (Barlow, 1991). Traditionally, oral diffusion was an essential aspect of the preservation of mana of knowledge and culture, since Māori were yet to use the written word to document distinct tribal histories and genealogies. Ideas and knowledge from historical traditional times are currently being reinterpreted in the present, which in itself incorporates a sense of continuity, of linking the past to the present. The interconnectedness with the kawai tipuna (primal spirits) is an essential link for Māori, validating the connections between the animate and inanimate worlds constituting the beginning of Te Ao Māori (the world of the Māori). Matauranga Māori is a complex and 'open system' (Salmond, 1985) which draws on

knowledge constituted and based on oral lore. According to David Williams, a Pakeha legal historian, Rangatira, (high ranking chiefs) and Tohunga (knowledge experts) maintained and articulated this knowledge (Williams, 2001).

Williams provided expert evidence in a Waitangi Tribunal hearing which is referred to by its case number, WAI 262. In his report entitled 'Matauranga Māori and Taonga – The Nature and Extent of Treaty Rights Held by Iwi and Hapu in Indigenous Flora and Fauna', he draws on the following definition of Matauranga Māori which states:

> Matauranga Māori in a traditional context is the knowledge comprehension or understanding of everything visible or invisible that exists across the universe…
>
> (Williams, 2001:4).

Essentially, William's report emphasises that: "Matauranga Māori not only contains potentially useful knowledge but also forms the basis of the Māori cultural paradigm" (Williams, 2001:11). In context of this thesis, the relationship between western science and Matauranga Māori is a constant theme found in the responses of three different groups of Māori to issues relating to genetic testing. The research participants utilise Matauranga Māori in different ways as they address the implications of genetics, human genetics and especially genetic testing. Members of each of the groups interviewed used this knowledge system to position and reposition themselves in relation to genetic science. The key concepts used within this knowledge system will be discussed in the following chapters and the use of these concepts by research participants will be explored. However, I also demonstrate the ways in which participants in this study use Matauranga Māori discourse together with discourses associated with western science and medicine, as they talked about the issues and implications surrounding genetic testing and bio-banking. In this respect the participants in this research used a range of knowledge systems, or potentially incommensurable paradigms (Kuhn, 1962), as they reflected on the implications of the new genetics.

The following section focuses on the Treaty of Waitangi and its relevance as a context for any discussion of Māori responses to issues raised by genetic testing.

10. The Treaty of Waitangi

The Treaty of Waitangi officially acknowledged the commensurable values and customs of both Māori and British. Signed between British representatives of the Crown and various Rangatira on February 6th 1840, Māori believed that they were entering into a partnership of good faith and trust. Two versions of the treaty were written and disseminated, one in Māori and the other in English. The English version of Article One of the treaty stated that Māori ceded sovereignty to the Crown, which gave the Crown the basis of its rights to govern. However, in the Māori version, Article One stated that Māori ceded Kawanatanga, which was a missionary transliteration of governorship and was a lesser form of sovereignty. The English version of Article Two stipulated that the Crown would guarantee Māori full and exclusive possession of lands, fisheries and other properties for so long as they wish to retain them. The Crown also received pre-emptive rights for all land tenure. The Māori version of Article II was understood by the Māori signatories as phrased in terms of a promise by which the Crown guaranteed continued rangatiratanga (utmost chieftainship) over lands, villages and taonga katoa (all their treasures). Article Three extended an obligation on the Crown to protect Māori and granted Māori all the rights and privileges of British subjects. Māori did not contest this latter article relating to citizenship.

In summary, the treaty formalised a partnership between Māori and the Crown as two commensurable entities. However, not long after the signing of the treaty, the Crown violated its treaty obligations through the use of both military force and legislation which, in complementary ways, undermined Māori rights guaranteed in the Treaty. Through government orchestrated land wars and subsequent legislative violations, Māori tribal society was broken down and the colonists sought to alienate Māori from their lands, fishing assets, language and ultimately, their world (Durie, 1994: 176).

The Native Land Act of 1908, known as the ‘taking lands’ Act, saw the individualisation of title replace the communal hapu entitlement to land. This individual enrichment constituted collective impoverishment since it was through communal ownership of land that mana was held amongst Rangatira (chiefs) for the prosperity of the people. Once there was no land, the Rangatira lost their mana amongst the people, and once this occurred, the people were disenfranchised and fragmented as individual whanau, no longer interacting so effectively in collective ways. This individualisation of land titles was consistent with the individualisation of knowledge that was occurring within a colonising New Zealand. The 'public institution' of the Tohunga was

repressed, for instance in the Tohunga Suppression Act (1907) (New Zealand Government, 1907). Individuals, rather than collectivities and lineages, became were often seen as repositories of knowledge. In a related process, the demonstration of individual knowledgeability became more dependent on success in a formal school and university system, rather than by integrating oral lineages with the abilities to coordinate collective endeavours. In the earlier half of the twentieth century, a British model of health professionalism became integral to a 'cradle-to-the-grave' system of state welfare provision in New Zealand. Previous systems of health care had become at least formally eclipsed by a centralised scientific system.

While the Treaty of Waitangi was not honoured after it was signed until the 1970s, it has since become is a significant basis for current land claims. It is seen by a number of the participants in this study (particularly the group of lawyers) as a key lever for Māori participation in discussion and decision-making about the use of new technologies such as genetic testing. The relevance of the Treaty for shaping debate about the implications of genetic testing and biobanking will be repeatedly considered in future chapters.

11. Scoping the Thesis

While Māori debate the benefits of science, especially genetic science, they have a shared set of understandings about the cultural, spiritual, and ethical aspects of their own society. These cultural understandings are grounded in the principles of whakapapa, mana whenua, kaitiaki, and the Treaty of Waitangi and positioned against a historical backdrop of colonisation, land confiscation, assimilation policies. There exists a deep sense of a lack of understanding of traditional Māori knowledge in New Zealand.

While sharing certain core understandings vital to Māori culture, Māori are also distinct in their particular histories of the colonising experience and are also now located as Māori in groups that are different with respect to their religious beliefs, professional training and political commitments. This thesis illustrates this diversity by exploring some of the variation in the responses of differently positioned Māori to genetic testing and biobanking. Three groups were interviewed as part of a larger study that involved facilitating discussion about genetic testing in various community organisations and social networks in different parts of New Zealand. Nine Māori specific groups, including a rural community group, a young mums group, a living with diabetes group, and an iwi group, participated in the research (Hipkins, 2004; Du Plessis et al., 2004).

The responses of the three groups of participants were shaped by their location in different fields of knowledge and expertise. The first group were Māori members of the Mormon Church (LDS) whose responses were primarily framed by the context of their religious belief. The second group also drew on spirituality as the basis of their practice, but their responses were more significantly shaped by their knowledge of Matauranga Māori and locally specific traditional understandings of health. The third and final group were drawn together because they had expertise as lawyers working in the context of New Zealand's capital city. The lawyers who participated were acutely aware of the role of the Treaty of Waitangi as a context for Māori participation in discussion of how genetic science might have an impact in New Zealand.

The differences and connections between the approaches of these three different groups to the issues raised by genetic testing for Māori are the focus of the three main chapters of this thesis. Through this discussion I hope to contribute to the development of understandings about the relationship between Māori and European knowledge/Matauranga through attention to complexities in the responses of different groups of Māori to genetic testing. I use the 'cases' of each of the groups of participants to illustrate how Māori negotiate between specifically Māori understandings and dominant global understandings about science and technology. Māori have been doing this since contact between Māori and non-Māori in the nineteenth century.

This research is driven by an interest in making available to people who work in the fields of health, biotechnology and genetics including relevant government agencies and privatised enterprises prevalent ways in which some Māori reflect on the implications of genetic science, particularly genetic testing. This work is also influenced by the diverse ontological perspectives at play as some Māori also engage critically with a series of issues relating to genetic testing. My approach resists a one-size-fits- all model for Māori. Instead it explores connections and differences in their responses to the new genetics, and to other boundary-shifting facets of science. I am particularly interested in the multiple and shifting boundaries between the understandings among Māori in a religious group, a group of rongoa practitioners and participants drawn from the legal profession. My focus is on how Māori within these groups conceptualise and negotiate the ontological positions they bring to talk about genetic testing.

The thesis begins with an introductory chapter which outlines and frames the concerns of participants and of the research. Chapter two outlines a contextual and theoretical framework that explores tensions between sometimes commensurable and sometimes incommensurable paradigms. Having located genetic testing within a discourse of science, I generate a brief

overview of common values and themes that constitute Matauranga Māori. This will set the scene for consideration of the four themes identified in participants' talk about genetic testing, whakapapa, kaitiaki, mauri and mana motuhake. I will consider these principles in turn. This chapter will also review some of the social theory that has shaped the thesis agendas and the interpretation of interview material. This includes discussion of elements of actor network agency and some reflections on Foucault's analysis of governmentality, power/knowledge.

Chapter three includes discussion of the research strategies and methodology utilised in this research. I will discuss the relationship between the approach of my thesis and the methodological framework developed by members of the broader Constructive Conversations/Kōrero Whakaaetanga research team and implemented in the three focus groups.

Chapter four considers conversation about genetic testing within a group of Māori members of the LDS church who belong to various wards within the Hamilton region of the North Island of New Zealand. I will look at how members value western science and western medicine, while also finding value in Māori frameworks understandings and knowledgeability about the world, yet always within the context of their religious belief.

Chapter five involves an analysis of the concerns articulated by a group of rongoa practitioners within the Taranaki region of the North Island of New Zealand. Central to this chapter is a consideration of the notion of kaitiaki or guardianship as the practitioners are immersed in traditional healing practices and are heavily dependent on natural resources and materials. I use ideas associated with actor network theory, and understandings of agency and kaitiaki in an attempt to explore the discursive practices articulated by rongoa practitioners who favour traditional methods of practicing health over genetic testing and western models of health.

Chapter six considers how a small group of Māori lawyers located their responses to the issues within the Treaty of Waitangi. I draw on the concepts of agency and mana motuhake in my reflection on their interpretations of the Treaty of Waitangi and its relevance for discussion of genetic testing.

The final chapter will identify points of commonality and difference across the three groups that participated in this thesis. This discussion is informed by a critical analysis involving conceptual tools from both Māori and social science traditions. Finally, both positive and negative responses by participants are used to illustrate how subtle conflicts and ambivalence are just as

characteristic of this area as are the stronger outlines of the major themes identified in earlier sections of the thesis research.

CHAPTER 2
A Thematic Overview

1. A Theoretical Roadmap

This chapter outlines the theoretical frameworks that informed this research. Ragin suggests that the process of 'casing' – the process of selecting and analysing cases – involves 'matching ideas and evidence by specifying which ideas are relevant' (1992b:221). Accordingly, this chapter looks at ideas that are relevant to the cases of negotiation among different knowledge systems that are at the heart of this thesis. I introduce a range of theoretical tools I brought to the analysis of talk among lawyers, rongoa practitioners, and members of the Church of Jesus Christ of Latter Day Saints (LDS/Mormons).[5] Negotiations among different knowledge systems were discussed and analysed by those who participated in contact group[6] and focus group discussions about social, cultural, spiritual, and ethical implications of genetic testing and biobanking.

Analyses of participants' conversations were not confined to the tools of social theory. Rather, this thesis required an interpretive understanding of the ways in which Māori research participants of diverse socialities used Māori conceptual frameworks to reflect on the implications of genetic testing and biobanking. For this reason, this chapter reviews not only selected theoretical frameworks developed by social theorists, but also Māori conceptual tools. In this respect, the thesis explores not only the interface between human genetics and Te Ao Māori, but also the interface between Māori cultural conceptual knowledge and social theoretical perspectives. Exploration of this interface would seem vital for informed policy-making regarding the challenges of new technologies, including the technologies associated with the constantly transforming field of human genetics.

The empirical focus of this thesis lies in the implications of genetic testing and biobanking, but the larger goal is to explore the intersection and interactions among alternative ways of being and knowing that include attention to matauranga Māori. My interest is in interfaces, boundary construction, and boundary- crossing, as differently positioned Māori actors negotiate the

[5] The LDS participants in this group identified themselves as Mormons and as LDS interchangeably.
[6] A contact group is a different from a focus group. See detailed descriptions and discussion in Chapter 3.

relationships between western science and tikanga Māori.[7]

Each of the sets of research participants in this study drew on four core Māori concepts in their conversations - whakapapa, mauri, kaitiaki, and mana motuhake. Discussion of each of these concepts will be complemented by attention to relevant social theory including Foucault's approach to power/knowledge and governmentality, the concept of actor networks, and ways in which social theorists have analysed agency. These conceptual tools will be used in Chapters 4 – 6 as I analyse the reflections of research participants. They constitute a commensurable set of analytic tools that will be reviewed in the concluding chapter of this thesis. In pursuit of these goals, attention will be given to a general conceptual understanding of the gene and the concept of genetics.

2. Conceptualising the 'Gene'

The aim of the geneticist is to isolate basic components of a gene at a chromosomal level, in an attempt to establish functions or causal factors that generate a specific outcome. Geneticists look for specific relationships, demonstrable mechanisms, or aggregate findings that allow them to make accurate and relevant statements about reality (Stricker, 1997). It is fair to say that the geneticist's conceptualisation of the gene is vastly different to how Māori conceptualise bodies. For Māori, the human, environmental, and metaphysical dimensions of bodies cannot be separated and disaggregated.

The rational reductionism of the orthodox geneticist appears to be incommensurable (See Kuhn, 1962) with Māori ontological and epistemological knowledge systems, which link all aspects of human and non-human life, including animate and inanimate objects. The Māori concept of whakapapa signifies and consolidates the normative living relationships between humans, nature, and the cosmos. Nevertheless, despite signifying and consolidating into a concept, whakapapa in practice resists reductionism. At the same time, Māori conceptions of the connections between different types of entities, different categories of being, and separated periods of historical time, are also commensurable with certain forms of scientific inquiry which seek to make and map these connections. These interactions and conflicts between related yet different conceptual maps and material worlds provide an uncertain foundation for this research. However, the very uncertainty permits and encourages a more accurate and relevant study by reflexively

[7] It seems significant that in some conversations, participants held that particular principles were non-negotiable.

emphasising the ways in which lived experience of research participants and researchers complements analytical understandings of technology and scientific philosophy. In the following section I consider a Kuhnian discourse of incommensurable and commensurable shifting paradigms. This discourse emphasises the interplay of science, social science, and Māori epistemological understandings.

3. A Kuhnian Discourse of Scientific Practice

Genetic science is situated within European constructs of an objective rationality developed by the addition of new truths to old truths, and in some instances, the correction of previous errors. Te Ao Māori is situated in a holistic context that encompasses spirituality and community. It invokes ideas about the interdependence of the cosmological, physical, and natural dimensions that make up human experience. In reflecting on the relationship between these knowledge systems and the way Māori research participants negotiated between them in their talk about genetic testing, I have found Thomas Kuhn's (1962) concept of paradigms, paradigm shifts, and incommensurability to be useful.

According to Nicholson, Kuhn "broadened the use of the word paradigm to mean 'the general frameworks of analysis which sometimes change in what he called a 'scientific revolution'" (Nicholson, 1994:1). Kuhn suggests that significant advances in scientific understanding do not usually arise out of the incremental advances of normal science, but out of 'paradigm shifts' when one set of ontological and epistemological assumptions are replaced by another set of ideas and associated scientific investigative practices. These paradigms are defined as 'incommensurable'. Since they are associated with different basic sets of ideas about the world and different ideas about what constitutes useful knowledge, ingredients of each approach cannot be used to critically evaluate the knowledge claims made within the other paradigm (Kuhn, 1962).

This thesis explores the relevance of ideas about paradigms and paradigm shifts (Kuhn, 1962; Nicholson, 1994; Coulter & Willis, 2004) for relationships between Te Ao Māori and contemporary genetic science. The complex relationship between these different knowledge systems, or paradigms was often negotiated by research participants in the three different participant groups.-

Te Ao Māori has been constituted through centuries of experience, language, and culture. It is

grounded within Māori conceptual tools including whakatauki (proverbs), purakau (pedagogical knowledge), and tikanga (principles and values). Genetic testing is grounded within the rational objectivity of western scientific assumptions about the physical world. Māori who participate in both the knowledge systems of western science and Te Ao Māori draw on understandings derived from both these paradigms. In this sense they occupy the uncomfortable boundaries between two incommensurable knowledge systems. I argue that Māori are constituted, like many other indigenous people, as those who have to juggle different paradigms. Sometimes they assert one paradigm over the other. At other times, they seek to render commensurable sets of knowledge claims that others find inconsistent or incommensurable.

Kuhn argues that "technology and society are mutually constitutive" (1962:22). He considers that it is mistaken to think of technology and society as separate spheres which merely influence each other. Science is inherently social and social life requires the knowledge which we refer to as ‘science’. Kuhn offers a social historical analysis of how science works, and sees change in scientific knowledge as the outcome of social processes. Kuhn’s assertions about science as social, cultural, and political constructs are endorsed in the work of Charles Moraze, who argues that modern science has its “roots in both the East and West of the Ancient worlds” (1979:26). For Moraze, Western science is an accumulation of knowledges embedded in different cultural traditions. However, indigenous knowledge systems are not recognised as contributing to scientific knowledge. According to most Western scientists, indigenous knowledge lacks authority and credibility because its 'localness' restricts it to the social and cultural circumstances of its production (Cobern & Loving, 1998; Stricker, 1997).

On the other hand, indigenous peoples assert the value of indigenous science and its value as ‘local’ knowledge (Fanon, 1967; Deloria, 1995; Tuhiwai-Smith, 1999a, 1999b; Irwin, 1994). “Situated or local knowledge systems have existed within a wide variety of cultures where the organisation of natural knowledge [is] intended to secure and improve– agriculture, irrigation, navigation, hunting and astronomy” (Watson-Verran & Turnball, 1995:117). I argue that matauranga Māori is situated within the values and concepts of an active worldview and that the Treaty of Waitangi is New Zealand’s first official attempt at asserting the commensurability of different knowledge systems. According to Tuhiwai-Smith, kaupapa Māori has a "set of assumptions and taken-for-granted values and knowledge upon which it builds, making use of Kuhn’s concept of paradigm" (1999b:7-8). This view is also endorsed by Irwin (1994). However, Tuhiwai-Smith also argues that Māori knowledge is framed, understood and reinterpreted within the discourse of the dominant knowledge systems of western science and philosophy, which she

argues, is incommensurable with Māori knowledge systems. These reflections on the incommensurability of Te Ao Māori and western science set the context for consideration of how different groups of Māori research participants engaged in issues about genetic testing and storage of genetic material using both Māori conceptual tools and sets of understandings that, at times, have been defined as incommensurable.

4. Situated Knowledge as 'Discursive Practice'

The concept of situated knowledge defines knowledge claims as specific to a particular situation or to the positioning of individuals within particular social worlds or forms of understanding. (Harding, 1998&2000). For instance, the concept could refer to an outcome of an experience, including education, training, religion, or a profession, which leads to individuals and communities becoming informed in various ways. Situated knowledge is commonly embedded in language, culture, history, or traditions. It is useful here to draw on Davies & Harre's (1990) observations about the way knowledge involves 'discursive practices'. They see people as positioned through discursive practices and argue that "individuals 'subjectivity' is generated through the learning and use of certain discursive practices …" (1990:1). The lawyers, members of the Church of the Latter-Day Saints, and rongoa practitioners who participated in this thesis research are constituted as subjects by the overlapping and distinct discourses they use in their conversations about genetic testing and biobanking. They brought to the focus groups discussions the situated knowledges they use in their everyday lives as Mormons, lawyers, and traditional healers.

Alander & Mörtberg (2003) argue that, once we recognise that knowledges are situated and socially produced, we have to concede that "there is no single, universal truth [but rather] different people possess and shape knowledge situated and located in geographical, physical, social and cultural experiences over time" (2003:5). While science purports to be value-free, indigenous knowledge systems are typically rich in narratives and are deliberately value-laden in that "in addition to providing knowledge about the environment … they also seek to provide moral rules and ethical guidelines which dictate proper conduct towards each other, and towards one's environment" (National Association of Māori Mathematicians, Scientists and Technologists, 2002:49-50). These value-laden knowledge systems were used by participants in this study as they talked about the implications of genetic testing and the storage of genetic data.

In the following sections of this chapter I explore the conceptual tools that participants utilised in

their responses to issues relating to genetic testing. Also highlighted are the social theoretical tools that I utilised to consider the complexities as Māori research participants considered the relationship between Te Ao Māori, and developments in contemporary human genetic science.

5. Te Ao Māori Discourses

There is insufficient space to fully review the literature on Māori ontology and epistemology embedded within Te Ao Māori discourses (Marsden, 1975; Barlow, 1991; King, 2003; Orbell, 1998; Mead, 2003; and Buck, 1977). According to Anne Salmond (1985), Te Ao Māori is a complex, 'open system.' Legal historian David Williams (2001), in a report to the Waitangi Tribunal, draws on a definition produced by Mohi who defines traditional Māori knowledge as constituted and based upon a "comprehension or understanding of everything visible or invisible that exists across the universe (i.e. Aorangi, sometimes referred to as Rangi and Papa)" (cited in Williams, 2001:15).

Traditionally, the transmission of knowledge and understandings of the world occurred through oral histories in the form of whakapapa, karakia, whaikorero, waiata, haka, patere, moteatea, and whakairo. The cosmological narratives in which understanding of the origins of the world and all living and nonliving things and their inter-relatedness are told and retold continue to be central to the transmission of Māori knowledge. The genesis of the world is premised with the realm of Te Kore, the nothingness which brought Te Po, the night. The embrace of Papatuanuku (maternal earth) and Ranginui (paternal sky) kept the world in darkness until Tane Mahuta son of the primordial parents separated them, bringing them into the realm of Te Ao Marama, (a world of light, potential and being). The offspring of Papatuanuku and Ranginui were delegated responsibility and kaitiaki (guardianship) over the elements of all natural resources, winds, crops, water, forests and mankind. Tane Mahuta also created human life by moulding the first woman out of clay and breathing mauri (the force of life), into her nostrils. Furthermore, common understandings among Māori are embedded in the transmission of knowledge and a perception of the world gained through oral histories in the form of karakia (incantations), whaikorero (rituals of encounter), waiata, haka, and whakairo (performing and visual arts) (Roberts et al., 2004; Marsden & Royal, 2003; Mead, 2004).

Tikanga and traditions in Māori society are neither static nor monolithic, but instead adapt to the ever-changing environment in ways that resist and incorporate aspects of a technological world. Concurrently, social theoretical constructions that underpin knowledge in the western world

provide ideas that have evolved and developed out of a long tradition of social interaction and observations of individuals as actors. In the following sections of this chapter I explore some of the connections between Te Ao Māori, contemporary genetics, and social theory developed in the field of science and technology studies. This discussion will involve exploring what is commensurable and incommensurable with respect to the different paradigms of Te Ao Māori and genetics. To this end I draw on the social theory developed by Donna Haraway, Michel Foucault, and those who have contributed to what is often referred to as 'actor network theory'.

6. Constructing Genes – Connections and Differences

While geneticists focus on genes and strands of DNA, Māori tell stories about origins and connection between people that focus on whakapapa. McKinley defines whakapapa as "based on knowing where an individual comes from in two ways, by descent or inheritance and the cultural practices and histories that belong to specific groups of people" (2003:19). Whakapapa encompasses the notion of kinship or blood relationships, usually linking through a common ancestor. Whakapapa is about the connections between individuals, hapu, and iwi. The manifestations of whakapapa are cultural and spiritual, involving connections between all things, animate and inanimate. Indeed, it is generally agreed that Māori value whakapapa because it is that knowledge which ~~that~~ locates and positions individuals in place, space, and time. It can be seen that whakapapa permits Māori to be Māori, as simultaneously individual and collective. The question immediately arising lies in whether Māori can continue to be Māori without whakapapa, or with changed concepts and practices of whakapapa.

Mead sees whakapapa as being "inextricably linked to the physical gene" (1995, cited in Glover, 2002:32) and is passed down the generations (Roberts et al., 2004; Mead, 2004). A Ministry of Commerce report states that Māori define a gene as a substance in the blood of ancestors: "...kei roto i ngä toto...(...it is in the blood...)...ngä toto o ana tipuna...(it is in the blood of his/her ancestors)" (cited in Cram et al., 2000:178).

According to Cram et al.:

> Genes are a part of the whakapapa relationship as animal or plant life. For Māori, a gene has Mauri that continues to exist ex-situ (when taken from its original place). The same perspective is carried over to issues of replication, trans-genetic engineering and cloning. Hence to alter the genes or genetic material is to alter the blood of the ancestors, altering the whakapapa relationship by changing or introducing new blood that may impact on the other rights that are passed down, rights of authority, status and control.
>
> (Cram et al., 2000)

In this respect Māori there is no disjunction between the spiritual and material worlds (Satterfield et al., 2005). Insects and humans, fish and ferns, stars and stones all descend from the spiritual realm of the atua (gods) and thus possess spiritual qualities (such as mauri) in addition to their own unique material qualities" (2005:45). This relational approach to genes is consistent with views held by Donna Haraway, who articulates the notion that a 'gene is not a thing'. According to Haraway:

> A word like gene specifies a multifaceted set of interactions among people and nonhumans in historically contingent, practical, knowledge-making work. A gene is not a thing, much less a "master molecule" of a self-contained code. Instead, the term gene signifies a node of durable action where many actors, human and nonhuman, meet.
>
> (1997:93)

Haraway's conclusion that a 'gene is not a thing' also overlaps with the Māori conceptual tool of Mauri, which is understood as the essence of life that constitutes things such as the gene, the meeting house, mountains and lakes as being relationally connected. The concept of mauri was consistently highlighted by participants as they spoke about human genetics, genetic testing and the storage of genetic information.

Wells states that: "…whakapapa begins with mauri, divine power or agency" (Wills, 2000:23). Fundamentally, the concept of "mauri is akin to the physical action of inhaling and exhaling the ha, (or breath)" (Satterfield et al., 2005:26). In this context, the notion of mauri is revered by Māori as the life principle that sustains the ihi (power, essential force) and wehi (fearsomeness) of all living things, animate and inanimate. Mauri provides all living things and every place with a unique personality. Mauri is vitally essential for all things, such as humans, lakes, and rocks, to exist "within their appropriate realm and sphere" (Satterfield et al., 2005:26).

Mauri is manifest in many different ways. In Chapters 4 – 6 of this thesis I focus on conceptualisations of mauri used by participants. Satterfield et al. (2005) reflect on the ways in which some participants in their study talked about the potential interference of mauri and disruption of the spiritual realm should that be a consequence of genetic modification. Their findings are consistent with the conversations that occurred among those participating in this thesis research and discussed in subsequent chapters. The concept of mauri as actively interconnecting and structuring lies at the core of whakapapa, and links all things which can be considered heterogeneous elements of the natural and metaphysical worlds. Attention in Māori cosmology to the network of relations between people and things is also analogous in some respects to the dynamic network focus of actor network theory (Law 1992; Law & Hassard,

1999; Latour 1993, Callon 1997). Actor network theory (ANT) approaches to theorising about people and things provide the focus of the next section of this chapter.

7. Actor Networks

A number of social theorists in the last twenty years have developed forms of analysis that look at the multiple ways in which objects, places, and people are connected. Attention to these interconnections distinguishes ANT. Neither people nor social structures are privileged in these analyses. Rather, the focus is on the complex networks of connections between people and things. ANT, accordingly, provides an understanding of nature and society that challenges western scientific rationality (Hall, 2005). In its attention to networks, and relationships between people and things, it overlaps with understandings of whakapapa and mauri.

Theorists associated with ANT propose that all elements within social life can be examined as negotiated networks in which any actor (including human, object, technology, and computer software) is socially[8] linked to a corresponding network of multiple actors (human and non-human). For instance, an ANT-focused consideration of genetic testing would explore the networked interplay among geneticists, counsellors, patients, consent forms, laboratories, test tubes, and DNA sequencing. In their attention to the relationship between material things such as DNA, consent forms, and differently positioned people, the actor-network approach is similar in some respects to Māori analyses that always consider the multifaceted relationships between people and things.

There is insufficient space in this thesis to provide a detailed analysis of the actor-network approach in science and technology studies. Instead I will highlight some important aspects of this approach that I think are relevant to this thesis. Actor network analysts see the world as made up of heterogeneous social and natural ‘things’. According to Hall “it is the connections that are crucial, rather than the things themselves” (Hall: 2005:2676). In particular, ANT does not privilege humans over things. Actor-network theory claims that any actor, whether person, object (including computer software, hardware, and technical standards), or organization, is potentially equally important to a social network. As such, societal order is an effect caused by the smooth running of an actor network. Any component might be critical, yet not all

[8] It is clear that social activity, according to ANT types of analysis, is a matter of communicative interaction of some real and observable type or other. ANT does not accept concepts of 'action at a distance'. There are always connecting movements of materials, people, non-human life, ideas, testing protocols, and symbolic objects, such as documents and regalia. This is not so much a clear-cut theory as a methodological principle of researching. Whether it implies or necessitates a particular paradigm, in Kuhnian terms, is a continuing area for research.

components are necessarily equal in their resistance to change and ability to influence others. Due to such uncertainties of agency, ANT emphasises the need for empirical case studies.

ANT draws attention to the heterogeneous nature of actor networks. This attention to heterogeneity is also evident in the work of Haraway who argues that "modern medicine is full of cyborgs, of couplings between organism and machine, each conceived as coded devices…" (1991:150). Both Haraway's analysis and an approach to studying the relationship between people and things that looks at heterogeneous relational networks (i.e. what is usually referred to as ANT) are consistent with the notion of whakapapa as integrative of all things in the world. Integration has been crucial for this research. As I negotiated between Māori conceptual tools and the tools of contemporary social science, I encountered commensurable ideas in what might superficially have appeared to be incommensurable knowledge systems. As a Māori researcher, seeking to use and understand Māori conceptual tools and those available from western social theory, these linkages were important. Making these connections shaped how I used the knowledge systems available to me as Māori and as a sociologist seeking to understand the ways in which Māori participants in this study negotiated between western scientific medicine, particularly human genetics and Te Ao Māori.

Some of the analysts earlier associated with the notion of ANT have rejected the label.[9] Those theorists who adopt this approach to research about the contingent and shifting relationships between people and things share to some extent traditional Māori conceptual frameworks that embrace a sense of the significance of relatedness and interconnectedness between people and things. In Chapters 4 – 6 I try, wherever possible, to follow the connections through which research participants thought about human genetics and the relational networks of genetic testing for them as Māori.

There were other ways in which talk about genetic testing led me to think about connections between the conceptual tools of western social analysts and those available through Te Ao Māori. I was particularly interested in the relationship between social scientists' ideas about agency, governmentality, and power; and Māori understandings of kaitiaki and mana motuhake. These relationships are the focus of the next sections of this chapter.

[9] Latour has indicated that he does not consider himself to be an ANT theorist and disputes the existence of ANT as a theory about the relationship between the material and the social. He remains interested in the process of analysis used by those who have been identified as actor network theorists, though disputes that there is 'a theory' (Law & Hassard 1999).

8. Discourses of agency, governmentality and power/knowledge

Emirbayer and Mische (1998) argue that the agentic dimension of social action can only be captured in its full complexity if it is analytically situated within the flow of time. They look at human agency as a temporally embedded process of social engagement informed by the past, but also oriented towards the future and towards the present. This analysis of agency is particularly relevant with respect to Mormon participants in this research. These participants actively move between social worlds of Māori culture and tradition, their Mormon religion, and their experiences of parenthood. They use these different worlds to constitute themselves as strategic and critical consumers of biomedicine and western science. Emirbayer and Mische also contend that: “as actors move within and among these different unfolding contexts, they switch between (or recompose) their temporal orientations – as constructed within and by means of those contexts – and thus are capable of changing their relationship to structure" (1998:964). In Chapter 4 I illustrate the ways in which these research participants exercise agency within their embedment in sets of ideas, times and places.

Foucault’s discussion of governmentality offers a critical analysis of attempts by individuals to exercise agency. He suggests that when people feel most active as agents, they are often engaged in processes of self-government that have their origins in dominant discourses. Attention to governmentality involves attention to the way in which power is produced through the actions of individuals who, while exercising agency, impose discipline on themselves and others in their day-to-day environments. Attention to governmentality involves attention to how power operates at the level of self-government and regulation of individual bodies and households, as opposed to the overt imposition of power on people by the state or government. Governmentality is at work when people act in certain ways to sustain or improve their health by eating certain things, avoiding other foods, ~~or~~ taking regular exercise, and voluntarily participating in regimes of surveillance such as population-wide genetic screening. Individuals are often constituted as those who can only be agents if they exercise this type of care, control, and expertise over their own bodies. This approach to governmentality is particularly relevant to the responses of rongoa practitioners to the opportunity to talk about genetic testing. Foucault’s understanding of governmentality (Lemke, 2001; Foucault, 1991; Faubion, 1994) will be considered in Chapter 5.

Foucault’s analyses of governmentality and his deconstruction of discourses of individual agency are closely related to his overall understandings of power and power/knowledge (Foucault, 2001). His notion of power is linked to a concept of pervasive domination that needs the agency

of people being dominated. Smart suggests that: “the sense of domination involved here is not that of one individual, institution, or class over the people or the nation, but the multiplicity of forms of domination exercised within the fabric of society” (Smart, 1983:82). Foucault contrasts the way in which power operates under modernity, through the self-government of individuals and households, with how it operated in pre-modern societies. There, he claims, power was centralized and coordinated by a sovereign authority who exercised absolute control over the population through the threat and open display of violence. Smart writes that Foucault’s interest in the body is determined by an interest in “how 'power' is exercised over the body, both by individuals who have internalized conceptions of the “normal” and by governments who collect information on bodies and devise new ways of regulating, disciplining, and routinizing them” (Smart, 1983:80).

Genetic technologies are potentially a new way in which individuals are offered opportunities for self-regulation, for example through access to information about their predispositions to illness, or their inherited genetic mutations that may prompt changes in life style such as decisions about reproduction. The routinisation of genetic testing would likely involve new discourses about ‘normality’ in which people would train themselves to become more responsible for ‘finding out’ about their genetic inheritance and more morally accountable for acting in ways that enhance the health and well-being of themselves and future generations.

Genetic testing companies currently offer tests within what Foucault would identify as a discourse of governmentality. People are invited to be active agents through using testing facilities, but are also constructed as problematically non-participants with respect to the location of knowledge in this field. Geneticists, scientists, and genetic counsellors are the holders of power/knowledge with respect to human genetics. The discussion of the responses of rongoa practitioners, Mormon Church members, and lawyers in Chapters 4-6 highlights some of their resistance to these invitations to exercise agency through accessing genetic tests, and other technologies associated with the new genetics. Their resistance is clearly associated with scepticism about the official sources of knowledgeability in this field. At times they challenged the power/knowledge of geneticists by asserting the value to them of different systems of knowledge.

9. Constructing Kaitiaki and mana motuhake

A collective exercise of care and control, rather than individual agency and personal power, is articulated in the Māori concept of kaitiaki (stewardship). The concept of kaitiaki was often referred to by participants in this study as they thought about the implications of genetic testing. The principle of kaitiaki derives from the kawai tipuna and draws on the specific duty of acting in accordance with tikanga to take care of - to exercise guardianship - for the benefit of a collective, usually whanau or hapu. The notion of kaitiaki is an ongoing responsibility of stewardship on behalf of the natural environment as it is understood that all things are related through whakapapa, as well as the obligation to maintain a life-sustaining capacity over the environment being ~~is~~ an imperative for human survival. The *Resource Management Act (1991)* formalises this duty in legislation (New Zealand Government, 1991). In this Act, s.7(a) makes explicit reference to a requirement that: "in relation to managing the use, development, and protection of natural and physical resources, [those subject to the Act] shall have particular regard to (a) kaitiakitanga, (aa) the ethic of stewardship, (b) the efficient use and development of natural and physical resources" (New Zealand Government, 1991).

Māori did not view the land in terms of private property, which was framed within the common law of ownership imposed colonially from the British Empire, nor did they apply the concept of guardianship on behalf of others. Māori held the land within the concept of kaitiaki, as a given, inherent right of collective responsibility to cultivate and utilise the land, or not, for the benefit of the people. The western view of private property extends to the notion of genes, genetics, and intellectual property, which can become commodified into forms of marketable property, owned by individual humans or hierarchical corporations. This is in stark contrast to understandings of collective responsibility articulated in Te Ao Māori. In Chapters 4-6 I will explore how participants in this research reflected on issues of personal agency with respect to decisions about whether or not they would access genetic tests and follow collective kaitiaki responsibilities for genetic material and the well-being of future generations. At times, a commitment to action that would enhance the well-being of future generations was associated with a positive response to using genetic testing and gene therapy. At other times, concern about collective rather than individual ownership of DNA was seen as an appropriate constraint on the agency of individuals with respect to the use of genetic technologies.

The final concept to be explored in this theoretical overview is the over-arching principle of mana motuhake. The principle of mana motuhake stems from the kawai tipuna, which is

particularly relevant in the way power was utilised by Rangatira. This concept was either directly referred to, or indirectly informed talk among research participants.

Before colonisation, the mana of a people was usually determined by the authority and power vested in a Rangatira (Chief) over whanau and hapu. This authority was entrenched in mana, land, history, respect, and social organisation (King, 2003; Salmond, 1997). Motuhake means to stand independent and promote autonomy. Attention to autonomy for Māori was a recurring issue for research participants as they expressed their concerns about biobanking, genetic storage, and predictive testing. Mana motuhake is seen as something which Māori lost and need to regain. This shaped the responses of the lawyers, Mormon Church members, and rongoa practitioners who participated in this study. For them, and for Māori participants in other groups within the larger Constructive Conversations/Kōrero Whakaaetanga (CC/KW) study, collective agency was potentially realisable through mana motuhake, the activation of collective mana, autonomy, and political power. For the lawyers, the Treaty of Waitangi was a key resource in the exercise of mana motuhake. Their conceptions of the relationship between Treaty discourse and genetic testing will be considered in Chapter 6.

10. Conclusion: Weaving Māori Conceptual Tools and Sociological Understandings

This chapter has attempted to introduce some of the Māori conceptual tools used by the three groups of research participants whose talk about genetic testing and biobanking is the focus of discussion in Chapters 4 – 6 of this thesis. The Māori concepts of whakapapa, mauri, kaitiaki, and mana motuhake are considered in more or less detail in each of the three findings chapters.

Some of the social theory I have found useful when analysing conversation among Māori research participants has also been introduced. Kuhn's understanding of scientific paradigms, Haraway's ideas about situated knowledge, the relationships between people and things considered by those identified as actor network theorists, and Foucault's ideas about governmentality have been briefly introduced and reviewed. I have also identified my interest in the ways in which some of this social theory may be commensurable, in Kuhn's sense of the word, with some of the Māori ontologies used by research participants and familiar to me as a Māori researcher and analyst.

The concept of whakapapa, for example, involves attention to human-non human interactions

and relationships. This focus on the relationships between people, animals, and things is consistent with the attention within actor network analysis to networks of connectedness among people, animals, plants, and other animate or inanimate actors. Aspects of ANT will be drawn on as appropriate to explore facets of relational and network thinking among those participating in the discussions which are the focus of attention in Chapters 4-6. The Māori concept of mana motuhake as an assertion of sovereignty and the right to exercise power is related to ways in which western social scientists have attempted to theorise about agency. This will be explored in subsequent chapters through attention to discourses drawn on and reinforced by research participants.

This thesis attends to complexities, networks, relationships, contexts and interactions between different knowledge systems though a close reading of talk in three diverse Māori groups about issues relating to genetic testing. The following chapter outlines the methodology and the research strategies used to generate talk about the social, cultural, spiritual and ethical implications of genetic testing.

CHAPTER 3
Research Methodology

1. Introduction

> The only true voyage would be not to travel through a hundred different lands with the same pair of eyes, but to see the same land with a hundred different pairs of eyes.
>
> (Marcel Proust cited in Bearman et al., 1999:3)

Qualitative research is based on the philosophical assumption that 'reality is constructed by individuals interacting with their social worlds' (Merriam, 1998:6). Accordingly, I will explore how the 'realities' of genetic testing and biobanking are constructed by three Māori groups located in social worlds differentiated by religion, health and law. My interest is in 'peeling back the layers' (Phillips, 2004)[10] of the understandings participants use as they occupy and negotiate spaces at the interface between their situated knowledges and dominant discourses of the western world, science and specifically human genetic science.

This chapter considers 'how and why' (Becker, 1996) I used certain methodological approaches, as opposed to others. This will be discussed in conjunction with the development of methodological tools by the wider Constructive Conversations/ Korero Whakaaetanga (CC/KW) research team (Du Plessis et al., 2004; Hipkins, 2004). I will also highlight some of the challenges that I encountered whilst embarking on this thesis and indicate what I learnt through this research process.

Whilst the attention to genetic testing involves a focus on western-based science and technology, the aim of this thesis is to present an approach to researching differently situated understandings of controversial issues that may be applied to other controversies and other fields in which it is important to access different voices.

[10] Minutes of Te Kopere Hui, 2004 – Comment by Dr Hazel Phillips

This chapter outlines the methodology of the participant-focused approach utilised in this research. It also discusses why I chose three particular groups of Māori participants. This discussion involves reflection on what Ragin (1992a, 1992b) refers to as 'casing'. The local research problems of selecting particular forms of empirical knowledge are utilised in a casing approach as a way of exploring and extending theoretical understandings and social analysis.

The CC/KW researchers had developed a general methodological framework prior to my joining the research team as a MA student. Their proposal to the Foundation of Research, Science and Technology (FRST) in October 2002[11] had identified contact group interviews with members of community organisations as their primary strategy for the first phase of this project which focused on implementing strategies for public discussion about new health biotechnologies. I was initially interested in carrying out a comparative analysis of issues related to genetic testing that were identified by Māori and non-Māori contact groups. This approach would have compared the responses of Māori with non-Māori participants. However, upon advice from another Māori researcher on the team about the rarity of Māori-specific research within the general area of health biotechnology, I decided to compare how three Māori contact groups responded to the set of research tools developed by the CC/KW team for use in the first round of discussions about genetic testing and biobanking. This approach forced me to pay attention to the membership, boundaries and locations of the groups, rather than to the somewhat problematic assumptions about the constitution of Māori as compared with non-Māori.

I am located as both an insider and an outsider in relation to the groups that are the focus of this thesis. My 'outsider' status relates to my professional location as a sociologist who analyses the responses of others and defines social issues. My 'insider' status arises out of my general commitment to sustaining Māori knowledge systems and cultural practices. It also is found in my sharing specialist knowledge held by LDS members, rongoa practitioners, and lawyers.

The framing of my research journey began in my honours year. I conducted a research project which looked at the implications for New Zealand's native harakeke (flax fern) of neo-liberalism, globalisation, and biotechnologies, including issues around intellectual property and patenting. Given that harakeke is used metaphorically in the Māori worldview for asserting positive relationships between humans, the environment, and the natural world, it appeared necessary to consider the potential hazards to this indigenous plant. At the same time I was studying the impacts and effects of the WAI 262 flora and fauna claim, which is based on Article

[11] Du Plessis, R. et al (2002)

II of the Treaty of Waitangi. WAI 262 provided a platform for future claims to protect nga Taonga tuku iho (treasures revered by Māori).

During work on these projects I had made clear to whanau, colleagues and participants my interest in researching the potential impact of health biotechnologies on local Māori community groups and organisations. I was invited to participate in the project as the first MA researcher on this because of my previous work and interests and was a recipient of a Masters scholarship within this research programme.

It was accordingly, appropriate and desirable that my personal networks and accesses were drawn upon in the selection of the participant groups. Other groups could have been selected to demonstrate arguably similar situated knowledges. However, access to Māori groups by researchers from outside those groups' networks has been problematic. It seems clear that exploratory research must work with the peoples and situations available, since controlled experimentation and random sampling are incapable of exploring unknown territory.

The following section positions cases and casing in relation to the overall thesis.

2. Cases and 'Casing' - Their relevance

Theoretical ideas and principles offer insights into and frame our structural descriptions of the empirical world. This thesis uses a set of theoretical ideas drawn from a number of different sources to analyse three ‘cases’ of talk about genetic testing and bio banking. It also looks at genetic testing as a ‘case’ of new health biotechnologies. Social science explanations are usefully understood as accounts of bounded cases, since this concept draws attention to the area and topic of inquiry, as well as its limits, location, differentiations, and historical division into periods. Ragin offers the idea that "cases can be observed behaviourally and that it is possible to assess the conditions under which social scientists are compelled to delimit or declare cases" (Ragin, 1992b:217). He also introduces the process of ‘casing’, understood as a focus on particular sets of empirical data to illustrate and or extend social analysis. Ragin argues that a case is built on interactive ‘casing’ components that are characterized by various levels of abstraction. At the very highest level of abstraction are theoretical principles that provide a framework for the investigative work that constitutes the ‘cases’. In this chapter, I explore the interplay between the abstract theoretical constructs considered in the previous chapter, and the actual group conversations that are analysed in subsequent chapters.

The three contact group discussions at the heart of this research project are explored as 'cases'. These are cases of connection and difference in Māori responses to new biotechnologies, especially developments in human genetics. The notion of 'cases' have been extensively written and observed by Yin (1989), Merriam (1998), Blaikie (2000), and Burns (1996). For instance, Denzin & Lincoln suggest that case studies are valuable "in redefining theory and suggesting complexities for further investigation, as well as helping to establish the limits of generalizability (1994:245). In this light, I decided to use cases that were connected to community groups that held, practiced, protected and constructed the particular forms of empirical knowledge I have attempted to explore. By this, I sought to accumulate information that would offer a "rich description of a single case/unit that considers the case's uniqueness, particularity and diversity" (ibid). Each of these contact groups was initially considered as a single case/unit that was both unique and had similarities with the other cases.

Case study approaches appear especially useful in public policy considerations of non-generalizable aspects of human experience, such as may characterise unique groups. In this respect, my choice of these three cases was consistent with Denzin & Lincoln's (1994) position, and with Yin's (1994) differentiation of holistic and embedded case studies. Yin states that a "holistic case study has only one unit of analysis while embedded case study's may have a sub-unit or a number of sub-units" (Yin, 1994:64). Accordingly, my three contact groups were sub units within themselves, but were also part of a wider sub unit of Māori contact groups facilitated by Māori researchers within the CC/KW team. This sub unit of contact groups used the same stimulus material as the other contact groups which were not Māori specific. They were also analysed separately, while at the same time researchers considered overlapping themes and issues (Du Plessis et al, 2004; Scott et al, 2005).

This specific research project focused on three unique community/professional/expert groups who identify as Māori. Each of these groups constituted a 'case'. I used the case study method in two ways; first, to elicit information from unique community/professional and expert groups about themselves and their boundaries, and second, to utilise genetic testing as a boundary condition which may be actively delineating a provisional case of new Māori health biotechnologies. The following section provides the rationale for using genetic testing and bio banking as a case for studying in this thesis research.

3. Genetic Testing and Bio banking as a 'case' of New Health Biotechnologies

The decision to focus on genetic testing and bio banking was made by the CC/KW team before I began this research. Genetic testing and bio banking are two examples of a number of possible forms of modern day science and health technologies. Any of these could have been chosen to illustrate the complexity and ambiguity of Māori responses to genetic science and more generally, to western science. I wanted to work in this field because these forms of new science appear particularly apt for eliciting responses to the relationship between science and other knowledge systems, particularly the systems of indigenous peoples. Why? The pace of new genetic knowledge and technologies is increasing dramatically. The new genetics and new genetic tests individualise access to and control over knowledge about human DNA. Genetic science has made possible the detection of precise genetic codes that can cause later physiological well-being, differences, and disorders (Jenkins, 2000). This is of interest because of the significant ethical, spiritual and cultural implications which such differentiation from group norms, and construction of collective identities, may pose in ways that current knowledge systems are not capable of addressing.

Previous diagnostic technologies involved taking family histories and analysing samples from other family members (Jenkins, 2000). The resulting information would then be shared by the whanau (familial collective). Current genetic testing technology, in contrast, enables sampling from a single person, and provides private, individualised knowledge about their own DNA and ancestors. However, these ancestors are common to other individuals, and to collectives, and to a lineage of ancestors and descendents. The individualising of these people and their relationships through a scientific method and conceptual framing provides parallel scientific explanations to Māori conceptual understandings of the world that have been embedded in whakapapa and in kinship linkages to common ancestors. The individualising potential of this technology poses challenges for indigenous peoples generally (Harry et al., 2000; Deloria, 1995) and Māori (Phillips et al., 2004) in particular, because this potentially conflicts with understandings about DNA and whakapapa as collective rather than individual. The complexities within new forms of health technology, including different forms of genetic testing (for example genetic profiling, predisposition testing and bio banking) are heightened by the limited forms of information available to general publics (Du Plessis et al., 2004).

This thesis illustrates the ways in which some Māori address these tensions. The focus on genetic profiling of newborns, direct-to-consumer advertising, and a hypothetical biobank initiative

(Appendix II) organised by a fictional Crown research organisation were possible ways of initiating talk about new genetic science, especially its application to human health. The focus could, for instance, have been on genetic testing and forensics. However, a collective decision was made to focus on issues relating profiling of newborns, commercial genetic testing and bio banking (Du Plessis, Scott, & Te Kopere Team, 2004).

3. CC/KW Research Strategies and Materials

This thesis employed participatory research methodologies that involved contact group discussions on genetic profiling, direct-to-consumer advertising and bio banking. These discussions were usually conducted in venues specifically linked to the organisations selected. The term 'contact group' was employed in 2002 by Anne Scott and Rosemary Du Plessis, to refer to contact groups recruited from existing community groups (Scott et al., 2005: 361). These contact groups were differentiated from focus groups in that they were contact groups drawn from existing networked community organisations oriented towards maintaining kinship, religion or professional groupings (Hipkins & and Du Plessis, 2004:3).

Drawing on the idea of networks, contact group interviews provided a context of collaborative engagement in social, cultural, political and spiritual endeavours. The contact groups encouraged sensitivity to small, yet significant differences in the positioning and repositioning of actors within various social worlds. This research strategy is useful for setting up and facilitating group discussions with Māori communities as the group process incorporates Māori values such as kanohi ki te kanohi (face to face) interactions.

Whilst this thesis has been based on contact group methods and analysis, I also utilised selected aspects of the more common focus group methodology. In this regard focus groups were a useful tool for eliciting a broader focus on the subject of genetic testing that could be narrowed down through appropriate thematic analysis. Focus groups were advantageous since they entailed networked participants exchanging narratives and points of view on genetic testing and bio banking. In this sense focus groups are ideal for exploring people's experiences, opinions, wishes and concerns (Kitzinger, 1995:299).

Lewis states that focus groups are a "carefully planned discussion designed to obtain perceptions in a defined area of interest in a permissive, non-threatening environment" (Lewis, 2000:2). This was particularly important in practice where a nurturing space encouraged participants'

disclosure of personal narratives about their own lived experiences. This was evident in both the LDS and Lawyers groups where personal information was shared that had direct links to the subject matter of genetic testing. In the LDS and Rongoa group interviews there was an initial discomfort about the notion of research and science as some participants were critical of the impact that research by those outside their communities has had on Māori. However, there was shift in both groups as individuals began to exchange points of views by addressing issues that emerged from the stimulus materials (See Appendix 2) that were part of the CC/KW interview strategy.

4. Tikanga - Ethical Practice

Standard social science research practice requires a commitment to good ethical practice. The overall CC/KW research project received ethical approval from the University of Canterbury Human Ethics Committee. In this case I did not need to apply for a separate process for ethics approval in the case of this thesis. However, the nature of the research I was undertaking required a process of engagement with the concept of tikanga, which is about an awareness of Māori kawa (protocol) and ethical practice which has been considered in the context of a kaupapa Māori methodology, an indigenous framework that utilises holistic forms of ethical relationality. This means relationships between researcher and participants are identified through whakapapa, and connections are made to relevant whanau, hapu and iwi. These connections, link two initial strangers, researcher and participant in a continuous web and flow of whakapapa connectivity. For example, although I am positioned as a researcher in the discipline of Sociology at the University of Canterbury, I am also a Māori researcher writing a thesis that privileges the understandings of Māori participants of diverse networks. In this light, the standard social science ethical codes of practice are important and consistent with the dynamism of kaupapa Māori methodology. The features of kaupapa Māori methodology have been reflected on by a range of Māori methodologists (Tuhiwai-Smith, 1999; Bishop, 1996; Cram, 1993; Cunningham, 2000) and critiqued by Marie (1999).

Tikanga includes concepts of mauri, manaakitanga, utu, whakapapa, tapu and so forth which determine relationships between people, environment, the past, present and the future. In this regard the CC/KW research team agreed to adopt ritualised processes derived from tikanga Māori in the facilitation of all the CC/KW contact groups, Māori and non-Māori. This was directed at ensuring that people felt that they were in a safe space to engage in dialogue about genetic testing. How the tikanga processes were used varied between different contact groups and among different researchers on the team (Hipkins, 2004; Hipkins and Du Plessis, 2004)).

5. Using CC Stimulus Materials

Three sets of materials were developed by the CC/KW project to facilitate talk about genetic testing and bio banking (Hipkins, 2004). The first stimulus was a hypothetical story of two parents confronting a decision of whether or not to agree to a blood sample being taken from their new born baby in order to create a 'genetic profile'. The follow up prompt for conversation was a fictional advertisement that promoted commercial predictive and susceptibility testing. The final stimulus was a pamphlet with information about a hypothetical biobank established by a fictional Crown Research Enterprise to collect genetic material (Hipkins & Du Plessis, 2004; Du Plessis et al., December 2004). Each of these three examples was informed by information or advertisements to which research team members had access. The mock advertisement drew on advertisements for genetic testing available on the internet, the hypothetical story about genetic profiling was informed by discussion of possible genetic profiling in a UK Department of Health White Paper (UK Department of Health, 2003), and the biobanking pamphlet was informed by the UK Biobank project.[12] I chose to utilise the CC/KW stimulus materials in the discussions I facilitated rather than develop materials specific to these groups, because I believed the materials offered a non-obtrusive way in which participants could access some information about genetic testing and biobanking.

Structured materials, questions and prompts were developed by the CC/KW project researchers and framed to elicit the connections between outcomes and decision-makers which Goven (2002a, 2002b) suggests is pivotal in the quest to engage in constructive discourse. Such connections were enhanced through processes of deliberation and ramification of the social networks of participants.

7. Recruitment of Māori members of the Mormon Church, rongoa practitioners and Māori lawyers

I recruited three contact groups namely, Māori members of the Church of Jesus Christ of Latter-Day Saints (LDS), rongoa practitioners, and a group of Māori lawyers situated in Wellington, New Zealand's capital city (Appendix V). I drew on personal social networks to recruit Māori members of the LDS church into a contact group discussion of genetic testing and bio banking. The rongoa practitioners and law practitioners groups where recruited through social networks of fellow Māori researchers on Te Kopere, the Māori caucus of the CC/KW team. The development of this caucus introduced the second phase of the CC/KW project. Participation among Māori in

[12] See Department of Health (2003) *Our Inheritance, Our Future: Realising the potential of genetics in the NHS.* London: TSO. and UK Biobank Ltd http://www.ukbiobank.ac.uk/

social science research, such as this project, often depends upon personal linkages within existing networks of trust and mutual benefit (Tuhiwai-Smith 1999; Cram, 1993; Phillips, 2004; Bishop, 1996; Stokes, 1992). Given the thesis was focused on genetic testing; it would have made sense to have invited Māori geneticists or scientists to share their views on the subject. However, the wider project was focused on securing the opportunity to meet with people in this field and due to the limitations placed on the thesis; I thought it best to concentrate on the three groups I selected.

Individuals who were networked through the LDS Church and individuals recruited in Wellington from the legal profession did not have any prior affiliation with each other. They had not met before as a group, although they shared beliefs as LDS members and legal professionals respectively. The geographical location of individuals in these groups was a pivotal factor for selection, since I wanted to access LDS participants who were affiliated to the Church within Hamilton, which is the location of the Church College of New Zealand and the LDS Temple. Geographical location was also significant in the case of the rongoa practitioners, who were all from the Taranaki region. Taranaki is of political, social and cultural significance because this was where hapu and iwi first experienced the adverse effects of the New Zealand Wars in the 19th century (Belich, 1996) and the Tohunga Suppression Act (1908) (New Zealand Government, 1908) during the colonisation of New Zealand. Wellington, New Zealand's capital city and legal centre, was the location for a meeting of Māori lawyers at which genetic testing and bio banking were discussed.

Each of these groups represents three crucial areas of relevant knowledge that has been identified as important when exploring the implications of new science, especially new genetics. These fields are: religion/spirituality, tradition knowledge/ matauranga Māori, and the law, with particular emphasis on the relevance of the Treaty of Waitangi regarding rights and protections available to Māori subject to the treaty. The groups were chosen predominantly to connect to these different forms of knowledge.

These groups were all predominantly composed of mature women. There were, however, a number of young women who were either recent graduates of law school employed in major law firms and a nursing student. Two older men also participated out of a total group of sixteen individuals across the three groups. This was noted in the LDS group as introductions were taking place when Hapi stated:

> It's with a bit of apprehension that I arrive and seeing that the status quo is being maintained in as much as I'm the only male, that's fairly representative, so once again it reinforces the whakaaro (idea) that mana wahine [strong women] is not such a concept but a reality.
>
> (LDS Group, 2003)

Across the three groups participants represented a smorgasbord of occupations including mental health, law practice, work in tertiary institutions, school teaching, work in government agencies, line haul transport industry, volunteers in community health, and other professionals.

The LDS and rongoa groups were contacted and interviewed in December 2003, and the lawyers were contacted and interviewed in early March of 2004. Second follow-up interviews were carried out in 2005 for all three groups as part of a follow up process for the CC/KW project. Workshops that drew together participants from different contact groups were also held in the middle of 2005. This thesis draws on discussion in the first round of contact groups.

A contact person was nominated by me for the LDS group in Hamilton and fellow colleagues from the Te Kopere team negotiated contact persons within the groups in Taranaki and Wellington respectively. I developed an information sheet (Appendix III), which followed a similar template to those used by other CC/KW researchers. The information sheet provided some basic background information about my role as M.A student in a wider research project, and invited the intended participants to participate in a contact group interview that would reflect on the implications of genetic testing and bio banking. Participants were made aware that I would be using the interview transcript in my thesis research and were informed about their right to withdraw their information or participation in the thesis and in the CC/KW project. It was agreed that post transcription of the interviews, participants would have an opportunity to view their transcripts and make adjustments where they felt inclined.

Once the contact people of each group received the information letter and consent forms (Appendix III) they disseminated the information to individuals in their networks who they considered may have had an interest in the contact group session. Following the selection of the participants in each group, a final letter was sent out informing intended participants of the logistics of the interview. This letter included, time, date and venue as well as a second copy of the details in the original information letters.

The following section explores the research process used in the CC/KW project more generally

and in this thesis project in particular.

8. Research Process

The structured interviews developed by the CC team lasted between two to three hours and these sessions were taped.[13] I also prepared some contextual questions (Appendix VI) in order to explore and consolidate my theoretical tools.

After I transcribed each audio taped interview, the transcript was returned to participants seeking feedback and clarification of their talk (Appendix IV) prior to the next phase of data analysis. The feedback from participants was generally good and apart from a few spelling errors, people were pleased with what transpired, although a number of people commented on how 'basic' their voice seemed when transcribed. In a follow-up letter I reassured participants that they should not be alarmed as oral conversations generally read differently to written text. I added that my analysis of the data would be under the scrutiny of a self-imposed "quality control" mechanism involving Te Kopere members.

(a) Implementation of tikanga processes - Korero tahi

The CC/KW project adopted tikanga protocols directed at creating a comfortable and non-threatening environment for all research participants (Tipene-Matua et al., 2004; Du Plessis, et al., 2004). The protocol included our facilitation as researchers assuming the status of hosts relative to the research participants. This was an interesting process, because in Te Ao Māori the hosting party is the tangata whenua, the people of that region. As researchers, we were manuhiri (visitors/ outsiders) and therefore the ritual of whakatau (welcoming) had to be exercised according to tikanga. In one instance, one participant commented on our process by saying it felt strange that we brought kai (food) to the Hui because we were the manuhiri. He felt it was his responsibility to host us and that we encroached on that tikanga. I responded by stating that we recognised their status as tangata whenua, yet that we as researchers were the reason why we have all come together to discuss issues about genetic testing, and therefore we felt it was our responsibility to assume the role of hosts. I shared facilitation of each of the groups with more experienced researchers within the CC/KW team assuming a range of different roles in the research process.

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[13] See Du Plessis et al. (2004); Hipkins (2004), Hipkins & Du Plessis (2004) for a full brief on the research processes used in the contact groups.

At the beginning of each group everyone present asked to mihi, to greet and to make connections with one another, and establish the purpose of their participation in the research. This section of the interview was full of rich narratives that reflected people's concerns, aspirations and sometimes their critical approach to science. These introductions were not taped, and yet in some instances participants would pre-empt a discussion on genetic testing by expressing the fears and concerns that they have of science and of research generally. I considered that the mihimihi sections presented opportunities for participants to speak freely about whatever it was they wanted to say about the topic which helped to set the ambiance and tone for the up later interview session. Following the mihimihi, a break in the meeting allowed for refreshments and also provided opportunities for people to meet and greet each other on an individual basis. After the break, consent forms were signed and collected and from that time the group interviews were taped. Prior to the interview, consent forms and information sheets were posted to participants a week in advance of the meeting. However, it was common for people to require new sheets and consent forms at the time of the introduction session.

Te Kopere had oversight over the correct incorporation of tikanga (the right way to do things). This approach was informed by the application of Joan Metge's short book *Korero Tahi* (2001) which discusses the processes used by Māori for productive conversations and their potential use in Māori and non-Māori groups, but especially when Māori and non-Māori are involved in conversation. This protocol was designed to assist prospective participants to feel comfortable. The integration of tikanga, which is primarily about the exercise of manaakitanga, (making people feel welcome and supported), was an essential element of the project. This process was used to facilitate productive, relaxed discussions about genetic testing within different groups.

(b) Limitations of Contact Group Interviews

Some of the limitations of group-based interviews involve situations where the voicing of collectively held positions may diminish the opportunities of individuals to express contrary views. (Kitzinger, 1995). This occurred in this research in situations where rangatahi (youth) were present and would not voice their opinions unless they were encouraged by research facilitators, or by kaumatua (elders), or by people in management positions. This was usually out of respect within hierarchal relationships between teina (junior) relative to pakeke (adult) and kaumatua/kuia. Some participants might have felt more confident than others due to gaining prior knowledge of the topic through other avenues. However, this provided an opportunity for rangatahi to engage in conversation without feeling like they were being scrutinized or criticised in a 'big brother' scenario.

(c) Critique of the materials used

Whilst participants were critical of the genetic testing debate overall, they were extremely adamant that sharing stories about themselves also meant stories about their families, their hapu and their iwi. These stories resonated with tapu knowledge. In order to tell their stories they needed to feel comfortable in the research situation and trust in the researchers was a crucial component. In this regard, the process of tikanga applied by the CC/KW team and this research is critical for engagement with a people who have negative experiences and few benefits from previous research. One participant drew on the importance of trust in a relationship, particularly when researching Māori:

> [Whaea] … I think it's really wonderful I always feel at ease when I know who I'm with and I really trust [your colleague] as a friend but also as a researcher so that was really important. Whoever she brings with her I would trust because of her so that's my trust in you comes through her, because of rangahau (research). I think we have to be very, because of genetic engineering very focused on who we are giving this information to, too and where its okay we feel alright that it comes back to us and we can just scrub out what we don't want there…
>
> (Rongoa, 2003)

In relation to the hypothetical story regarding genetic profiling, Hohepa stated outright that he believed the scenario we presented was not in alignment with a Māori experience. He explains:

> [Hohepa] ... I think it's an unfair, the example you gave, in one way, because what you are actually doing is giving a Pakeha story. If you were giving a Māori story you probably won't have the same answers in the same way. If you are up in the Marae you would say "now this is your whanau, this is your whanaunga we are talking about here." Now you are going to see a lot of emotions start to stir up because they look at everything as being very linked and interconnected to what we do. That's why the story in itself, it does not create discussion. What happened is that you've told a story where it's very clinical. It doesn't take into consideration, Māori. In reality, there is a reason why I have never been in favour of cataloguing, because it takes away your personality. It takes away you; it takes away your development, the way you want to develop …
>
> (Lawyers, 2004: p8-10 342-443)

This sentiment about the stimulus materials reflecting Pakeha values was common amongst the groups and was most overtly articulated by members of the rongoa practitioners group.

Some individuals across all three groups were critical of the stimulus materials because they were neither in the Māori language nor Māori specific, and therefore are not reflective of Māori experience generally. I was encouraged to utilise a Māori health model in my thesis research, such as Te Whare Tapawha, publicised by Mason Durie (1994) which is referred to in the LDS chapter. Hopeha one of the participants in the lawyers group criticized the research tools as too clinical, and offered an alternative scenario of how this subject could be received more positively in Māori contexts:

> [Hohepa] ... If genetic testing is going to be useful, make the language simple; make it so my Uncle Jim can understand it. Don't make it so complicated that Uncle Jim can't understand or Aunty Mary, because all you are going to get is distrust. So it falls down to those concepts as well. If we took this venue here, the Marae where we have a lot of people, we could have the same debate, because the majority of our people would have just stuck to the tikanga side and we would probably have our point of view because that's how they are. If you took it to a venue where it is tūturu Pakeha [non-Māori], it would be interesting that they would have a different view...
>
> (Lawyers, 2004)

However, the Mormon group claimed the interview process was straightforward for example:

> [Mahina]... I just want to congratulate you on your processes, because I thought your processes were very respectful …
>
> (LDS, 2003:35)

Another participant from the same group was initially shy and felt the process to be a little daunting, but had this to say about the overall process:

> ... I see this [genetic testing] is all new and like when the internet first came out it was not long before a lot of things went wrong or people were misusing it before others got hurt that suddenly the government thought okay lets put something in place so people cannot abuse the service. The internet is so huge and fast that this is what we can see happening with genetic testing. So this process is vital and I hope it actually makes a difference…
>
> (LDS, 2003)

A participant in the lawyers group viewed the bio bank brochure that had a photo of a group of multicultural individuals on the cover and asked "Where am I in this picture?" (Lawyers, 2004) The lawyers talked about the need for information that was appropriate for a Māori audience

and would reflect experiences of Māori. Hohepa, a Māori lawyer, expressed the notion that the materials needed to be explained "in our language" (Lawyers, 2004). Emphasis was added by Mere from the same group who explained:

> [Mere] ... I had a similar experience when they [researchers] were doing [a] rural commission on genetic modification a few years ago. I went along to a …consultation Hui (meeting). I was the only young person and all the rest were our Kaumatua and Kuia who live on the Pā and were interested and wanted to come along. That was a waste of time really because the information, the way they disseminated it, if you hadn't had a basic understanding previous to going along there about what genetic modification is, what genetic testing is what a gene is, you couldn't really participate. That is what I found. I didn't understand what was going on. From the feedback, I think that was quite consistent throughout the mōtu, of our people on the ground. The way the information is disseminated isn't the way that it was readily accessible to them. The participants said that they have got even more pressing issues that they have to deal with-how to feed their kids, have we got enough money to pay the rent this week, all those issues come into it…
>
> (Lawyers, 2004)

(d) Venue for meetings

The research process I employed in the context of the Mormon group included securing a meeting place that would resonate with them and their core beliefs. I contacted a participant recruited from my social network within the Mormon Church to facilitate the recruitment of other members of the Church within the Hamilton region. Through the support of the principal of the Church Collage of New Zealand (CCNZ), a venue was organised for the Mormon group at CCNZ, which is situated in the shadow of the LDS temple (Appendix VIII). This was a significant choice of venue for one of the participants who stated:

> [Aroha] ... I'm grateful for it being here (CCNZ). If you had of said to me it was going to go out in the Marae, I would have been grateful but it would have put me in a different mindset. That's why I'm grateful that it's here [Church College of NZ], because this is a part of me, the 'bigger' part of me...
>
> (LDS, 2003:32)

The other Māori researchers within the Te Kopere team recruited contact people from their social networks. They recruited people for the interview, as well as the venues. For instance, the rongoa practitioners' meeting was held in the workspace of the practitioners. This location invoked a spiritual experience from within the realm of Te Ao Māori for me as researcher as we were welcomed into their space of hauora, (wellbeing) and healing. The participants greeted us

in the formal way of Māori tradition with a whakatau similar to our own process of introductions and waiata were exchanged. The lawyers' meeting was co-ordinated and facilitated in a Wellington office space that was made available by one of the CC/KW project team members. The law participants recommended at the end of the meeting that a future meeting could be held at the Māori Legal Services Office, which I had not previously considered as a venue.

(e) Group Dynamics

As previously mentioned each group was nominated by a member of Te Kopere. A contact person from each group assisted in the organisation of recruiting participants to the contact group meeting. Not all participants were familiar with each other and so the mihimihi process at the beginning helped to put participants at ease, as people were already anxious about the genetic testing debate let alone talking about it in a room full of strangers. The LDS group, gelled together nicely as they each asserted their agency and common ground within their Mormon faith and knowledge base. Individuals in this group were not dominated or subsumed by the stronger members of the group. The rongoa group on the other hand was comprised of the lead expert of the organisation and two workers and a young administrator. The group dynamics were different to the LDS group in that the younger members would wait to be prompted or wait for the elder member to voice and opinion or comment. Aware of these dynamics early on in the interview I began to direct questions to those individuals who were quiet in the discussions. The elder member also prompted them to contribute. However, this was very seldom. As a result the rongoa chapter is predominantly informed by the expert and one of the three workers. At the same time the lawyers expressed their viewpoints with confidence. Although, one of the participants was much older and tended to interject quite often whilst the two younger participants explained their positions, there was a very strong supportive group dynamic.

9. Reflection on the Research Process

Qualitative research involves attention to how meanings are embedded in actors/peoples/participants experiences. According to Merriam these meanings are mediated through the researcher's own perceptions (1998). Moreover, Merriam states that "the key concern is [in] understanding the phenomenon of interest from the participants' perspectives, not the researchers" (1998:6). Reflection on the methodological tools I used, made me aware that I had anticipated that Māori responses to genetic testing would be easily elicited using the research

materials. My interest was in establishing how Māori understood genetic testing technology and the information that derived from genetic testing knowledge.

The researchers provided kai and the utilised aspects of tikanga (Cram et al, 2005) including; mihimihi, kai, and poroporoaki (farewell) in order to maximise the possibility of a relaxed atmosphere that encourages people to share ideas and engage in conversation without any hesitation. The importance of attention to food was highlighted by Hapi in the LDS group:

> [Hapi]... My recommendation to you is that whenever you are dealing with Māori, it is always safe, good, to have kai on the table. So if the budget will allow, put on some, and if you want to throw in some seafood that is even better. I commend you on that, because I think whenever you're running a whare wananga[14] as you are that that is in keeping with protocols that Māori would abide by and respond appropriately to…
>
> (LDS: 2003:33)

In the LDS group I decided that it might be useful on the day to video tape the interview. I had not indicated this in the information sheet I had distributed, but requested permission from people on the day. I wanted primarily to look at my own research process and think about how I could do things better for the following two groups. There was general agreement, and I proceeded with videotaping the interview. I had two audio-tapes, a digital recorder an audio cassette and a video tape. At the end of the interview, one participant expressed his discontent with the videotape:

> [Hapi]: I think I can speak now because the camera is no longer on.
>
> (LDS, 2003)

The participant also stated that he did not like that I'd "sprung it on them" (LDS, 2003). He preferred that I use the audio tapes and discard the video footage as my intentions for its use were not clear. I thanked him for his input and said that I would not use the videotape. I decided not to pursue videotaping the next two groups. I reassured him that the audiotape files would not be used for anything else but the intended purpose and that they would be securely stored.

On analysing the transcripts and engaging with relevant literature, I realised that the Māori participants' conceptualisation around the issues of genetic testing was articulated on a continuum of future, past and present. The participants used the opportunity to discuss genetic testing as a chance to talk about what was important to them. This was not necessarily what

[14] Whare wananga is used in reference to a Meeting with a specific focus that is ongoing.

seemed of most relevance to researchers. However, the participants' narratives of their lived realities and experiences as Māori often invoked knowledge of a diverse people, a colonised people, and a people involved in different social contexts by which the production of a richly descriptive discourse may well emerge. Participants articulated their responses in an intelligent and eloquent manner that attests to the mana of the people who participated in this research. The responses of these groups were shaped by their location as Māori and demonstrate both active and resistant utilisation of a common set of understandings about whakapapa, kaitiaki, mauri and mana motuhake. This process illustrates the constructive way in which such core Māori concepts are being re-interpreted in the 21st century. In undertaking this journey I have embarked upon personal discoveries through trial and error. My research is equally an account of my journey to this understanding.

10. Analysis

The thematic analysis of the interview material was developed in two stages. The first stage was an analysis developed within Te Kopere, the Māori research caucus, using a collaborative framework of Māori conceptual tools identified across the nine Māori contact group transcripts. The second stage included my use of social theory that would illustrate points of connection and difference across a Māori thematic analysis of the three Māori contact groups' transcripts that I chose as cases. Each of these stages is discussed below.

The first thematic analysis employed in this thesis was developed within a Te Kopere members analysis of Māori contact groups transcripts transcribed in 2003 and 2004. Individual Te Kopere team members engaged in initial readings and rereadings of transcripts that identified key themes, which were discussed at subsequent Te Kopere Hui. These themes reflected values, cultural beliefs, and spiritual practices, including individual and collective responsibilities that incorporated both Māori and English meanings and understandings. Te Kopere members began to identify the domains of significant importance that reflected people's responses across all nine transcripts. For this thesis, I engaged in a similar analysis. As a team we identified four main concepts. These were positioned as an analytical framework that illustrated the interconnected relationship between nature, science and the spiritual realm. Whakapapa, mauri, kaitiaki and tino rangatiratanga and mana motuhake emerged as key themes (Du Plessis et al., 2004: 14 - 20). These themes enabled us as team members to consider the complexities across, and the ambivalences within, the various contact groups. For instance, the Māori lawyers group reflected on the stimulus material used in the interview and highlighted a number of issues that they

thought we should have addressed as Māori researchers in this project.

The second thematic analysis involved my role as M.A student in the field of sociology. After reflecting upon the transcripts and a framework of Māori conceptual tools developed by the CC/KW team, I began to review social theory that might be relevant to the themes identified by the Te Kopere team and those that were particularly relevant to the three groups that were the focus of my attention. I talked about the Māori conceptual themes to my non-Māori[15] and Māori supervisors who advised me on relevant theoretical issues. At first I considered themes around conflict theory, grounded theory, and social contract theory, but found that it was difficult to integrate these approaches and the agendas set out in the opening chapter of this thesis. I reviewed the literature in the field of resistance, resilience, and post-structuralist notions of agency, but found these were also unsuited to my research goals. My supervisors encouraged me to consider a wider range of analytical methods. I then selected the social theoretical tools reviewed in Chapter two with respect to power/knowledge, governmentality, actor network theory, and agency.

11. Complex positioning – researcher and thesis writer

As I worked on this project I was an M.A student in sociology, conducting research within a wider social science research team. This presented both challenges and opportunities on a personal and professional level. I was initially invited by my supervisors to engage in a thesis project that would reflect on the CC/KW's methodological approach particularly the use of tikanga processes within a mainstream research project. However, the opportunity to focus on particular Māori contact groups with specific attention being paid to the connections and differences that might emerge from their talk, seemed a more feasible and exciting task. As Māori and as a researcher, I had responsibilities among Māori participants' to ensure the needs of my participants were met and that the research processes I was facilitating were clear and transparent. Participants had the option of withdrawing consent from participation of the contact group interview process at any time. This extended until the final write up of this thesis research.

In the first phase of the project my primary supervisor, who was American born, accompanied me to the North Island to work alongside me during my first contact group interview. This was with the agreement Māori and non-Māori members of the CC/KW team. Not long after this

[15] First Phase of thesis – Primary Supervisor Dr Anne Scott and Secondary Supervisor Rosemary Du Plessis (both Sociologists) and tikanga Māori supervisor Dr Hazel Phillips (Kaupapa Māori Researcher and Educationalist). Second phase of thesis – Primary Supervisor Rosemary Du Plessis and tikanga Māori supervisor Dr Hazel Phillips

meeting, fellow Māori researchers began to advocate a kaupapa Māori methodology which meant that Māori contact groups in future would be conducted by Māori researchers and analysed by Māori researchers only, unless agreed otherwise. In this context, the second phase of the CC/KW project to developed. It involved more distinct Māori and non-Māori research teams which worked relatively autonomously, but in partnership and in parallel (Cram et al, 2004) with each other. It posed challenges for me as a thesis student and for my Māori and non-Māori supervisory team.

As a thesis student, CC/KW participation team member, and Te Kopere member, I found the task of writing a thesis daunting. Report writing and presenting at various conferences nationally (Māori Research Conference at EIT in Napier, 2004)[16] and internationally (Bioethics Conference, Sydney 2004)[17] provided exposure to various networks of people doing research in genetics, public health, social science and indigenous studies. This thesis is written against a backdrop of the dynamics of interactions at conferences and the complex experiences I had as a M.A thesis student, Māori, doing social science research in a wider project.

The following concluding section to this chapter presents a summary of the methodology, and its links to the goals for this thesis.

12. Conclusion

The objective of this thesis is to explore the heterogeneity and connection in the ways in which differently positioned Māori have responded to the challenges genetic testing and bio banking. In this chapter I have explored the concept of cases and casing and I have provided information about the contact group research process used in this thesis. I have also considered recruitment of three specific groups, LDS; Rongoa and Lawyers, why they were selected and the environments in which these groups discussed genetic testing and bio banking.

To conduct tika research that reflected both social science and Māori value, it was an imperative step to form relationships of trust, particularly when Māori are cynical of research practices generally. This is due to Māori experience with research that has often marginalised,

[16] Eastern Institute of Technology (EIT) is situated in Napier, North Island, New Zealand. In December of 2004 EIT hosted a 'Māori Research' Conference. As a member of Te Kopere I co presented a discussion involved around a methodological approach that looked at the engagement of Māori research within a mainstream research project.
[17] Bioethics Conference Sydney, November 2004 I had an opportunity to present a poster on my view of genetic testing and Māori engagement thereof from the perspective of religion, alternative health and law. See http://www.bioethicsworldcongress.com/ (accessed 25 March 2006).

misrepresented and created problems for Māori. As I embarked on this research I realised that just as non-Māori may impose their values and beliefs over Māori, there was the danger that I might impose my own hapu/iwi values and beliefs over other iwi members. For this reason, I chose to focus on conducting focus groups and analysing interview transcripts where the participants had links to me individually or to other members of the CC/KW research team. I do not claim on the basis of discussion in these groups, to represent Māori responses to genetic testing and bio banking. What I hope to do is illustrate the knowledge systems used by differently positioned social actors which are both diverse and overlap.

The following three chapters present in some detail the connections and differences in responses of the three contact groups chosen as 'cases' of Māori responses to genetic testing. The first of these three contact groups to be considered is the Māori members of the LDS Church.

CHAPTER 4

Constructing LDS Views on Genetic Testing

I was born into a religious home where my parents were members of The Church of Jesus Christ of Latter Day Saints more [commonly] known as Mormons. Through my mother, I was nurtured to believe in Deity. Deity was knowing there were three separate members of the Godhead; the Father, his Son, Jesus Christ and the Holy Ghost. I was encouraged to learn for myself and to study these truths by my mother, my church leaders and teachers. In my studies, my personal experiences and my desire to know these and other truths I stand independent and say I know there is a Godhead consisting of my Heavenly Father, the Father of us all; his Beloved Son even Jesus Christ, the Creator of this earth, and the Holy Ghost that testifies of these truths. This is the foundation of my religious belief. All my decisions in life are influenced under this belief and I am not persuaded to surrender these truths and beliefs.

Religion is significant in my life. It was easy to accept at the knees of my mother for she was my principal teacher and exemplar and I was safe. My dad was the teacher of tikanga Māori but with respect, I did not follow him easily.

My experience with genetic testing was with my second oldest and youngest sons who were tested for mental disabilities. When I learnt that Fragile X was in the family, I sat my children down in Family Home Evening[18] and away I went through this Fragile X thing so they could have as much knowledge as I have.[19] When the doctors found what was wrong, I was asked to bring the families in for testing. None of my family, either my Mum's or my Dad's would even talk about it so there were no tests. I later learnt that in Melbourne, Australia there is a clinic set up for the disabilities my boys have. I believe I carry the gene and am now working up the courage to have the test carried out on me. If this is what genetic testing is, I would not want this information to be public. It's hard enough to live with the thought that I carry the defective gene, but to put it out there for public display is too difficult to consider. If I had known I was going to have children with disabilities, would I have changed my mind if I had gone in for that test? As far as being a church member is concerned, I accept a child coming that way. I understand the need for genetic testing and that there could be progress in having genetic testing, however, it frightens the heck out of me about what that information can do.

(Aroha, LDS, 2003).

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[18] Family Home Evening is an LDS activity that encourages families to participate in learning about the teachings of the gospel together through singing, sharing and having fun with each other.

[19] Fragile X is a family of genetic conditions, which can impact individuals and families in various ways. These genetic conditions are related in that they are all caused by gene changes in the same gene, called the FMR1 gene. Fragile X includes FXS (fragile x syndrome) the most common cause of inherited mental impairment. This impairment can range from learning disabilities to more severe cognitive or intellectual disabilities. Symptoms can include physical and behavioural features, delays in speech and language. (For more information refer to the National Fragile X Foundation http://www.fragilex.org/html/home.shtml)

1. Introduction

The personal account which begins this chapter highlights what Phibbs claims are the 'politics of spaces in which narratives, events, identities and experiences are at play' (2001:20). Through her narrative, Aroha articulates the complexities of her diverse sociality – her location in diverse, but overlapping social worlds defined by religion, ethnicity, and motherhood. She conveys what it means to be a member of the Church of Jesus Christ of Latter-Day Saints and how this is considered within the context of her cultural identity as Māori. Aroha also considers how these socialities may impact on her capacity to make decisions about her whanau, her children with Fragile X, and what she can do with that knowledge.

Her unequivocal confidence in negotiating life decisions is dependent on her relationship with Deity and an adherence to the gospel principles she identifies in this extract from her contribution to discussion among LDS Church members in Hamilton. However, her adherence to LDS religious principles is in contrast to Aroha's experience within Te Ao Māori, which she is less inclined to follow, despite its importance for her father.

While prioritising some of the knowledge systems which are important to her over others, Aroha has articulated an integrated matrix of diverse socialities. LDS conceptual tools are most important in how she engages with such matters as genetic testing. At the same time, she draws on her experience as Māori, and this has an impact on how she articulates her perceptions about genetic testing. Aroha's ability to mix together and move between these distinct social worlds provides some insights into the synchronicities, or points of convergence, between social worlds and knowledge systems.

The complex weaving of knowledgeability which Aroha articulates is echoed by remaining members of the Māori members of the LDS group who engaged in discussions regarding the potential impact of genetic testing. Like Aroha, LDS participants give priority to Mormon doctrine when considering any decisions regarding their use of technologies such as genetic testing. They also drew on the ontologies and epistemologies of western science and Tikanga Māori as they talked about genetic testing and biobanking. This chapter will explore how participants used the conceptual resources of an LDS faith system, and other knowledge systems, as they responded to the stimulus materials prepared by the project team to facilitate their talk about specific applications of genetic science.

I begin this chapter by mapping the ontological terrain of the LDS church, since this provides a context for these church members' situated knowledge of the Church doctrines. This mapping will assist in the later discussion of how participants use their LDS knowledgeability, Te Ao Māori, and their everyday life experience as they contemplate the possible impact of genetic testing on their lives and those close to them. An in-depth analysis of the transcript of the LDS discussions in Hamilton in 2003, and follow up interviews in 2004, contributes to an understanding of how these Māori members of the LDS articulate their concerns about genetic testing and the storage and ownership of genetic information.

2. Mapping a Terrain: An LDS Ontology[20]

The LDS members who participated in this research are located within various wards of the church in the Hamilton region that are determined by suburban boundaries. The LDS church does not distinguish its members in terms of their ethnicity, gender, or any other social status. The LDS church views all people as descendants of Adam and Eve, the first parents of the earth created in the image of God.[21] The Church asserts that when Jesus Christ was upon the earth he organised his church, enabling people to receive his gospel and, as a result, one day returning to live with their Heavenly Father. According to Mormon belief, after Jesus' mortal death, his apostles were killed and members of the Church began changing the teachings he established. This became known as the state of apostasy, or the general falling away from the truth that resulted in the withdrawal of Christ's church on earth (See http://www.lds.org/). However, in Acts 3: verses 9-21, the Apostle Peter prophesised that Jesus would restore his gospel before his second coming (Church of Jesus Christ of Latter-day Saints, 1989).

Within this context, Mormons testify to the knowledge that the latter day or modern day Prophet Joseph Smith restored the Church of Jesus Christ of Latter-Day Saints upon the earth in the nineteenth century. In 1820, as a 14 year old boy, Joseph Smith entered a grove of trees and sought wisdom as counselled in the Epistle James 1:5 "If any of you lack wisdom, let him ask of God, that giveth to all men liberally and upbraitheth not, and it shall be given him" (Church of

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[20] Photograph of an LDS Maromaku Branch, Northland, New Zealand – 1950, Owner Phoebe Waihoroi Wetere, Thompson

[21] Church of Jesus Christ of Latter-Day Saints (1989) The holy bible, Genesis 1: 27

Jesus Christ of Latter-day Saints, 1989). Joseph asked the Lord which Christian denomination he should join. His answer was revealed when the Lord and his son Jesus Christ appeared before Joseph. It is written in the Joseph Smith History, 1 verse 19, that the Lord answered that he must join "none of them, for they were all wrong" and "all their creeds were an abomination in his sight". He said that they had a "form of godliness, but they denied "the power thereof" (Church of Jesus Christ of Latter-Day Saints, 1989).

The LDS shares with other Christian denominations a belief in God the eternal father, His Son Jesus Christ, and the Holy Ghost. The LDS Church is distinguished from other religions through the practice of exercising[22] sacred covenants in sacred temples that are directed towards the achievement of eternal salvation. The Church relies heavily on four standard religious works, namely the Book of Mormon, the Doctrine and Covenants, the Pearl of Great Price, and the Bible. These are used to assist in church members' understandings of the gospel of Jesus Christ.

3. LDS address the impact of genetic testing

Māori members of the LDS church articulated how their core beliefs and understandings within the Church derive from the example of their parents and Mormon doctrine. This is illustrated in the following extract from the transcript:

> [Mania] My father felt that if he did what he knew to be the right thing he could secure his relationship with his family for eternity through work done in the temple. I decided to know for myself if what my father believed was true or whether he was conned. I have learned since through the experience of positive reinforcement that God is real, he does live, he has restored his true church upon the earth and that I am a part of this wonderful human family of which He (Heavenly Father) has great and wonderful things planned of each of us …
>
> (LDS, 2003)

This sense of connection with the higher power is also shared by Aroha and other Māori members of the LDS Church participating in this research. These church members intelligently articulate a myriad of complex issues. These issues are important to them as LDS members, as Māori, and as citizens of New Zealand society who may be asked to address its implications for them and their whanau.

Analysis of the transcript of conversation in this group led to the identification of certain key

[22] The LDS carry out sacred ordinances in temples that are secure families together for the eternities. This will be explored further on in this chapter as LDS participants articulate their responses to genetic testing.

themes. The first theme consists of the participants' belief that the decisions they make in life should involve consultation with the higher power through faith, good works, and prayer. What is of importance to them should be a reflection of gospel doctrines. The focus is on eternal life rather than the day-to-day implications of developments in human genetics or any other frontier of contemporary science.

A second theme involves attention to the notion of family unity as a fundamental part of Mormonism. This includes the notion of genealogy or whakapapa as a way of linking past, present and future generations. I utilise genealogy and whakapapa interchangeably as this is how the participants engaged in explaining how modern doctrine and ancient scripture encourages the intergenerational unity of the family unit, not just in the present, but for all eternity. The goal of achieving this unity in eternity extends to care-giving or kaitiaki over relatives who were not baptised into the gospel prior to their death. In these circumstances sacred ordinances are carried out in order to cement the bond between family members for all of eternity. This shall be explored in further detail below.

Finally, the third theme considered is the concept of agency. This section of the chapter looks at Mormon Church members' hopes, fears, concerns and aspirations about genetic testing and its impact on their families in the future.

The following section begins with an articulation of members' reliance on Mormon teachings and gospel principles when thinking about science, medicine and human genetics.

4. LDS Explicit Confidence in the LDS Faith

From the start of the interview with LDS participants clearly stated their beliefs based upon ancient and modern day scripture and revelation and their centrality for their responses to any of the questions to be posed about genetic testing. One person who was invited, but unable to attend the focus group interview, wrote a letter stating her convictions about the LDS Church's position on the beginning of humankind and the sacredness of the body (Appendix VII). Statements from LDS members often combined the belief system of Church of Jesus Christ of Latter-Day Saints with Te Ao Māori:

> [Moana] We believe in God (Io), we know he created us in his own image. We revere that Deity created human kind and all that exists in the world. We know that prophets lived and guided us

> from the beginning. We also know that through the teachings of our tupuna, that we are a chosen and prestigious people who, through our diligence and obedience to the laws of a Heavenly Father, including honouring and looking after our bodies, we will inherit once more when we leave our mortal existence, regain a beautiful exalted body. However, we will not enjoy this blessing if we choose to allow science to desecrate this same body…the Church teaches us the sacredness of the body. It is also important for us to know who we are. We are the children of a Heavenly Father. We are created in his image.
>
> (LDS, 2003).

This statement integrates beliefs of the Mormon Church with reference to understandings of tupuna and the significance for Māori of whakapapa. Belief and everyday practice are closely connected. As members believe in the resurrection of people as expressed in the quote above, priority is given to increasing spiritual obedience in order to attain a strong relationship with the creator. Another participant endorsed the doctrine above quote by stating that:

> [Mahina] A relationship with Deity provides a very rich sense of self, such as language, identity, thoughts and conversations including strong family ties that eventually create a recipe for a healthy lifestyle
>
> (LDS, 2003)

In response to questions about the possible genetic profiling of newborn babies, Mahina declared that for her "genes are not the sole determinants in our lives. There are social, cultural, and psychological aspects of human nature that are just as important as the physiological" (LDS, 2003). However, another participant saw genetic profiling as a potential danger zone for children because it creates information that may be accessible to others and there are ramifications that could spring from the availability such knowledge.

> [Pikitia] I think it's unfair to the little person to have their genetic test done because their whole life map is out there on the records. It can potentially be given to employers or insurance companies that could discriminate against them when there is a high probability that they will not even contract a disease. That is enough to pose them as a risk
>
> (LDS, 2003).

This view was also shared by participants who were concerned for the future welfare of children and the potential situations in which a genetic test could discriminate against individuals. Mahina expanded on the conversation around potential risks to include the idea that medical practice is continuously evolving because they do not have all the answers. She stated that the scientific medical community have claimed a monopoly on all good knowledge, but suggested that "there

are many other ways of approaching health…" (LDS, 2003).

Participants used their own life experiences as well as their religious beliefs to reflect on the implications of genetic testing. Mania in particular drew on her personal experience as a young child and the consequences of these experiences when thinking about the possible impacts of genetic testing. Her life was shaped by growing up in a hospital as a result of contracting polio and meningitis. She considers the positive consequences of integrating diverse knowledge systems including western health, rongoa medicine, and LDS knowledgeability:

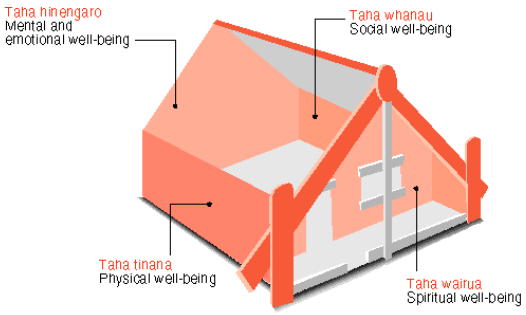
> [Mania] I have a sense of security with western health. I also have a sense of security with rongoa Māori because I also had that in between the hospitalisations where my grandmother would fix things with leaves and other things…and so I have a founded knowledge of both. On saying that also having priesthood blessings every time I got ill was my sense of security. This was because my father, I believed, had the authority to summon an audience with the creator. Then I felt that I was in good stead, and the positive reinforcing I got from all of that caused me to continue to want to be aware of all that.
>
> (LDS, 2003:4).

The LDS members were explicit in their expressions about what knowledgeability they could draw on when they were challenged with regard to health and life generally. While Mania reflects on the importance of using a range of different ways of pursuing healing, another participant reflected on the utilisation of Māori specific models of health and well-being, including the Whare Tapawha. Developed by Mason Durie[23] (1994:70) the model of Whare Tapawha, figuratively speaking, can be considered as an analogy that draws on the four walls of a whare with each wall representing four fundamental aspects of human health, hinengaro, tinana, wairua and whanau.

The first wall 'hinengaro' (mind) is responsible for the mental and environmental wellbeing which ensures coherent thinking processes. This involves acknowledging and expressing thoughts and feelings and responding constructively. The second 'wall', 'tinana (body) is concerned with physical wellbeing with regard to the physical body, its growth, development, and ability to move, and ways of caring for it. Third is the wairua (spirit), the spiritual wellbeing where values and beliefs determine the way people live and find strength in their search for

[23] Dr Mason Durie's whare tapawha model compares hauora to the four walls of a whare, each wall representing a different dimension: taha wairua (the spiritual side); taha hinengaro (thoughts and feelings); taha tinana (the physical side); and taha whanau (family). All four dimensions are necessary for strength and symmetry.

http://www.tki.org.nz/r/health/curriculum/statement/page31_e.php



meaning and purpose in life, and personal identity including self awareness. Finally, the concept of whanau is concerned with the social dimensions of health to enable family relationships, friendships, and other interpersonal relationships; feelings of belonging, compassion, and caring; and social support.

Mahina was concerned about the possibility that genetic profiling of newborns would lead to people being defined in terms of their DNA rather than their relationship to the Creator or other people. She stated that:

> When we're looking at these different things [reference to genetic tests] they do not do anything for protecting our wairua. They do precious little for protecting our hinengaro, and tinana because everything is focused on the body. What we know for certain is that when people have a very strong sense of their spiritual nature, they've got a very strong relationship with the Creator. They also have a very rich sense of self, their language, their identity, the way they think and talk. They have strong family relationships and that in itself has more to do with good health than just determining what's going on with their genes
>
> (LDS, 2003).

Within this context of Te Ao Māori and LDS knowledgeability, the participants drew on understandings of spiritual, mental, and physical wellness and their relationship to the goal of eternal salvation. Their sense of wellbeing is closely linked to their spiritual development and their relationship the Creator. This shapes the very rich sense of self that is expressed in their language, their identity and their way of negotiating different ontologies and epistemologies. While the focus group discussion was on genetic testing, the LDS members used the occasion to reflect much more generally on what they considered was most important in their lives and those of their family through historical time.

Many of the participants talked about an understanding of the pre-existence, and plan of salvation and eternal life. LDS members believe in a pre-existence where humans were 'spirit children of a Father, God' (Church of Jesus Christ of Latter-Day Saints, 2006). Members of the LDS church believe that all human beings lived with God in a pre-mortal existence prior to gaining a body. The next stage is mortal life which is a temporary existence. The final stage

follows mortal death when all those who have gained bodies will rise in the resurrection to an existence to which there will never be an end. The participants' knowledge of the eternity is described in the Book of Revelations. One of the participants spoke about 'that day of healing will come where bodies, which are deformed, and minds that are warped will be made perfect" (LDS, 2003). It is this understanding of a future in which perfection will be achieved that shapes LDS responses to genetic testing.

This knowledge provides a basis for the acceptance of children with disabilities. All the participants expressed the view that God has a divine plan for all his children. For Aroha her role as a mother and caregiver of children with disabilities has been pre-ordained in the pre-existence. This shapes her response to the recognition that there is something different about two of her children:

> [Aroha] I know who I am as a member of the church. If I had of known I was going to have children with disabilities would I have changed my mind if I had of gone in for that test? I did not want to go there. I was not interested in whether they were disabled or not
>
> (LDS, 2003:14).

Realising that two of her children displayed behavioural problems different from other children Aroha became concerned. She took the children to be tested, and discovered they had Fragile X syndrome (FXS), an inherited disorder expressed in the form of intellectual disability. While accepting that their imperfection may be part of an eternal plan, she nevertheless uses the diagnostic innovations of genetic medicine to 'find out' what is wrong.

Use of contemporary genetic medicine led Aroha to discover that there were various options available to her and her children.

> [Aroha] I later learnt that in Melbourne, Australia there is a clinic set up for the disabilities my boys have. At the meeting where I learnt this I believe I carry the gene and am now working up the courage to have the test carried out on me.
>
> (LDS, 2003:28).

Aroha combines her belief that God has a divine plan and the need to adhere to the gospel principles with access to information available through western science. She uses both to inform her children about the genetic inheritance of Fragile X and the importance of following the gospel. She seeks to construct her children (including those of reproductive age) as active agents

and expresses the view that they should have an understanding of Fragile X and be able to make their own decisions. In this instance, Aroha's children and their prospective partners have opted not to be tested, and to accept any children they have as they are. In regard to genetic testing, Aroha accepts the progress technology offers as means to prevent disabilities that could affect future generations. However, since Aroha's investigation of the condition of her children, her extended family members have refused to talk about or acknowledge the tests. Presently Aroha has relocated to Australia for personal reasons and has indicated (private correspondence) that she is working up the courage to be tested herself. Aroha's response to genetic illness in her own family is to utilise the knowledge systems of both western medicine and Mormon belief. She and her family negotiate between these different knowledge systems. Her contribution to discussion in the contact group illustrates some of the challenges of these negotiations.

In caring for the wellbeing of their children and future generations participants in this contact group often referred to genealogy/whakapapa as the key to attaining eternal salvation. Their belief entails carrying out of sacred ordinances, including baptisms for the dead in Mormon temples directed at ensuring future salvation and eternal life for those who were unable to be baptised prior to their death. The next section of this chapter looks at ideas about family, whakapapa, and kaitiaki with regard to discussion in the contact group about genetic profiling, direct to consumer testing, and the banking of DNA information.

5. LDS Value Family Togetherness for All Eternity

As participants reflected on predictive genetic tests that could potentially provide information about susceptibility to disease, discussions focused on the importance of families not only in the present, but particularly in the future - post mortality. As Moana explained: "We believe in whanau mo ake tonu atu [Families together forever]" (LDS, 2003).

Members of the LDS church believe that all human beings have the opportunity, whether in this life or in the next, to accept or reject the gospel of Christ. They cite 1 Peter, where it is written that only through the total immersion of baptism can individuals enter the Kingdom of God (Church of Jesus Christ of Latter-day Saints, 1989). The following verse of the bible supports this focus on the baptism of those already dead:

> For this cause was the gospel preached also to them that are dead, that they might be judged according to men in the flesh, but live according to God in the spirit. (1 Peter 4:6)

According to Mormon belief those who have already passed on, who did not hear the gospel or receive baptism, may be baptised by proxy. Someone who is in their mortal state can stand in for them. This is set out in the Doctrine and Covenants:

> Thus came the voice of the Lord unto me, saying: All who have died without a knowledge of this gospel, who would have received it if they had been permitted to tarry, shall be heirs of the celestial kingdom of God; Also all that shall die henceforth without a knowledge of it, who would have received it with all their hearts, shall be heirs of that kingdom; For I, the Lord, will judge all men according to their works, according to the desire of their hearts. (Church of Jesus Christ of Latter-day Saints, 1989: The Doctrine and Covenants chapter 137 verses 7-9).

This understanding of their responsibilities towards the dead and their own place in a much larger divine plan underpins the way Māori members of the LDS church construct their viewpoints about genetic testing. For LDS members, concern among Māori about whakapapa was closely connected to responsibility among them to ensure the salvation of their own and others family members through baptism, since this is the only way people enter the kingdom of heaven. This was the way in which Pikitia expressed this idea:

> [Pikitia] I think as far as being an LDS member is concerned, whakapapa is really important because of the work that we do for our kindred dead. Whakapapa to me is the link that we are not all just here individually or with our own immediate families or those that we are just related to now. We all link back to Adam and Eve and to me that's whakapapa
>
> (LDS, 2005)

As licensed temple patrons of the church, LDS participate as proxies to ensure that spirits who have gone beyond the mortal state of existence are baptised and therefore have access to eternal life.

> [Moana] We believe that mortality is only a stage of living and that we can prepare for an eternal and exalted life after we die and are resurrected
>
> (LDS, 2003)

Baptisms for the dead[24] are carried out regularly in Mormon temples as way of obtaining

[24] "While souls in the spirit world are being taught the Gospel (read Doctrine and Covenants 138), they are faced with a dilemma. They need baptism to enter into a covenant with Christ and receive a washing away of their sins, etc., but they lack physical bodies in which to be baptized. This is why the early Christians and the restored Church have the practice of baptism for the dead, referred to but not explained by Paul in I Cor. 15:29. This passage alludes to a practice of at least some early Christians who performed vicarious baptism on behalf of deceased ancestors. This practice in the Church of Jesus Christ of Latter-day Saints is NOT derived from 1 Cor. 15:29, but from modern revelation which restored that practice and the understanding and

salvation. Members believe that because God wants all His children to have the opportunity to return to Him, He has provided a way for those who have died without these ordinances to receive them (Walsh, 2006). Those who died without the opportunity to receive the gospel are therefore baptised (1 Peter 4:6; 1 Corinthians 15:29) by proxy in sacred Mormon Temples.[25]

A participant linked the concept of kaitiaki to the role LDS church members have on earth for securing the future of those who have already passed on. The church figuratively speaking acts as kaitiaki for the ancestors by ensuring their eternal salvation is secured through the practice of these specific covenants.

> [Mania] I guess kaitiaki comes into this area too by way of my personal responsibility to those that have died and the importance that as LDS we believe that being dead does not exempt our dead from the needs of taking care of certain obligations here on earth. This is why temples are erected so that we can do these certain obligations that need to be adhered to, that have been outlined in the scriptures for our kindred dead, and so we are not just talking for our Maori people, we are talking about for all of Gods children. The last time I went through to the temple I represented someone from France and so I have then, what I feel is a personal responsibility to my brothers and sisters not only those who are alive but those who have passed on. And I'm sure most LDS people that have an understanding of the gospel have this kind of sense of responsibility too. And as a link in a whanau it becomes my responsibility to ensure that all of my children and my tipuna are connected, that I make sure that those connections are made and thereby hopefully through all of my posterity. But I have a personal responsibility to safeguard and to link up.
>
> (LDS, 2004).

Mania went on to develop the concept of kaitiaki and its relevance for LDS practice. This discussion involves weaving together aspects of traditional Māori belief and LDS religious understandings:

> [Mania] [if] we look at how the concept of kaitiaki and how this was valued anciently it is different from today's world because we see things differently. For example, recently we were down at the marae and the morepork had flown on the flagstaff and it just sat there. My sister in law commented on how she felt that this was her sister [who passed away] watching over them and how she felt about that. When we talk about these things whether it's the morepork – I know in Hawaii there is talk of the tiger shark being their kaitiaki of the ocean – where I am from up north we have the sting ray and the fantails… all these animals, these creatures have certain significance

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authority necessary for it to be done. As a result, members now can go to the Temple and be baptized by immersion in the name of specific deceased ancestors and others, one at a time, name by name, offering our vicarious service as a proxy for the deceased" (http://www.jefflindsay.com/LDSFAQ/FQ_BaptDead.shtml)

[25]The NZ Hamilton temple is the only temple in NZ that has sacred grounds. Entry into the temple is restricted to worthy LDS members of the church who hold temple recommendations mandated by high officials in the church.

> to hapū and Iwi. When I consider these things, I honestly believe that yes, these things are in place until we gain a higher understanding. Until we can know for ourselves as individuals and people that God lives, that he is the creator of us all, both children, animals and everything a like. That until we know these things for ourselves these things have their place. And until such time that we become aware of the creator and our role to him and his authority that is left on earth, until we can make that connection and until that time these things virtually do have to become our keepers until we are capable of being in touch with deity ourselves. Once that happens, I believe the animals go back to being real animals
>
> (LDS, 2004).

Participants are aware of the various spiritual dimensions accessible through religious practice. Whilst the domain of animals is associated with the realm of Tane Mahuta, Kaitiaki and caregiver of the forests, their security of Deity brings a sense of calmness for the participants. Participants in this focus group spoke about the way in which LDS practices were directed at celestial glory,[26] the ultimate goal for LDS members. At the same time they were interested in integrating their Mormon beliefs with Māori beliefs about the sacredness of animals and the physical environment:

> [Pikitia] But then just understanding that those animals were sacred and they were there to protect us or to warn us of things. Like the fantail and the morepork in Whangaruru. With being LDS then you get that greater understanding, being able to get that security from Deity yourself without having to go through any channels is what being an LDS allows you to do. So you do not have to rely on that or some unknown power to protect you or your whanau. You're able to rely on Heavenly Father and Christ supreme (LDS, 2004).

The LDS members were primarily focused on their relationships with Deity. This is what has most impact on members' everyday lives. In this respect, agency was important to them. Participants articulated a strong sense of agency and constituted themselves as those capable of making decisions regarding the use of available genetic tests and the storage of genetic information.

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[26] Celestial glory is that glory which is attained through obedience and active participation in following the Mormon doctrines (Church of Jesus Christ of Latter-Day Saints, 1989).

6. LDS Utilisation of Agency

Aroha's narrative at the start of this chapter encapsulates scientific knowledge about the genetic condition of her children. Despite accessing the tests that have led to the diagnosis of her children, she does not embrace the agency of intervention to ensure future generations will not inherit the disease. Aroha exercises her agency in a way that is linked to her spiritual knowledge. For instance, in the case of human genetics, geneticists can investigate possible genetic defects and sometimes provide suggestions about interventions (including decisions not to conceive) that could avoid future problems. However, for Aroha and other LDS, agency is best pursued as a form of spiritual connectedness rather than attention to physical perfection in one's mortal life or the lives of one's children or grandchildren. Agency is best achieved through the baptism of the dead – by engaging in acts to save those who have died, rather than focusing on improving genetic outcomes for the next generation. As Māori, the LDS acknowledge their diverse linkages to whanau, hapu, and iwi groups that constitute individual identity. However, as members of the LDS Church, their priorities are confirmed by their spiritual beliefs and testimonies of God and the church. Essentially, LDS who are worthy of temple recommendations[27] are agents of change as they perform works for the dead that enable them to have opportunities to live in exaltation. LDS demonstrate their agency through the ordinances of baptism and strive for perfection through adherence to the teachings of the gospel, rather than through the use of information about their DNA or that of their children or grandchildren.

Throughout their narratives, these participants articulated a strong set of opinions that were steeped in the philosophical traditions of the Church. Members advocated a strong desire to make choices with respect to the use of genetic medicine that were consistent with their beliefs and the values of the church. Often participants shared how this belief system manifested itself through the power of faith. Indeed members affirmed their belief in the gospel of Jesus Christ of Latter-Day Saints and declared that they would not under any circumstances surrender to any other influence that may challenge their faith and belief system. They stipulated that, where conflict arose it is immediately eliminated in favour of the church teachings and principles. In regard to storage of genetic information, members construct their knowledge from a divine plan that has been set before them by Deity: decisions are made accordingly.

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[27] Temple recommendations are a form of licence that is approved by a Bishop and a Stake President after a personal interview.

It is this faith in Deity that Aroha uses to sustain and support her children who are affected by the Fragile X gene, or who may be carriers who can pass it on to their children. Belief in a plan of salvation and its relationship to information about human genetics were articulated by Aroha:

> …there were some children that needed to come here to earth and I was a good vehicle. If they came having a disability I was fine with that. I haven't had any problems about that. I have never thought any differently, but that I was just one of the ladies that could just look after people with disabilities. So that crossed religion with an everyday living aspect. It was not just because of one area or another. It was a logical thing for me. I know who I am as a member of the church. If I had of known I was going to have children with disabilities would I have changed my mind if I had of gone in for that test? I did not want to go there anyway. I just was not interested in that, disabled or not.
>
> (LDS, 2003:14).

Aroha's acceptance of children with disabilities rests on her LDS knowledge about pre-existence and the role that the plan of salvation plays. Members believe that prior to birth spirits lived in the pre-existence spirit world. Heavenly Father made it possible for spirits to receive physical bodies in order to prove their worthiness to return to live with him once more. It is within this acquired knowledge that Aroha confidently accepts her role as mother in order for special spirits to have bodies. This is further endorsed by another participant in the group who suggests:

> [Mahina] I would really like to talk about the antenatal tests where there are already women facing huge pressures to have terminations of their foetuses when they find out adverse information. There is a lot of pressure placed on the mothers to have terminations of pregnancies, and, it is a very strong family that objects, says NO. You know when convictions are such [as expressed by Aroha] that we (LDS) are going to welcome any child no matter what happens. And that makes a difference…
>
> (LDS, 2003:16).

While Aroha contemplates using genetic testing to find out whether she is indeed a carrier for the fragile X gene, she also accepts, as part of a divine plan, the challenges of rearing her two sons with Fragile X. She will not act to prevent the birth of a child with a disability, but she might want to know about whether she has the gene. This involves the exercise of a strategic agency that is shaped by spiritual belief and associated understandings of identity. As Moana articulates:

> It is also important for us to know who we are. We are the children of a Heavenly Father. We are created in his image. We believe that mortality is only a stage of living and that we can prepare for

> an eternal and exalted life after we die and are resurrected. The teachings we accept as gospel speak of respecting, honouring and caring for our bodies. We also learn of the sanctity of the body. The commandment given to Adam and Eve, our first parents to multiply and replenish the earth is still relevant to us today. Abortion is not sanctioned.
>
> (LDS, 2003).

These beliefs provide the context for Aroha's welcome of her children with a disability. They are a way in which she can exercise kaitiaki within the LDS Church by giving unborn spirits the opportunity of life and salvation. Agency for Aroha is not exercised through a reproductive decision making shaped by knowledge of the Fragile X diagnosis of her two sons, but through acting to keep her family together for all eternity. For Aroha, this mortal existence is a mere speck of time which does not account for much in the bigger scheme of things.

Some participants saw LDS philosophies and Te Ao Māori as forms of commensurable knowledge and practice, whilst others were more ambivalent about the relationship between the two ontologies:

> [Pikitia] Even the migration… to Aotearoa and …the karakia that was imperative to our people to secure safe passage here. The selection process – people who secured a place on the waka and all those who came on the waka were chosen for a specific purpose. They were blessed and there was a karakia over those people. So right from back then our tupuna followed Atua and they went with what we acknowledge as the Holy Ghost. Our people were led by the spirit, so as far as I'm concerned that's what we do in the church, we are led by the spirit.
>
> (LDS: December 6 2003).

Pikitia has articulated the notion that certain practices of the LDS church are consistent with tikanga and kawa adhered to by Te Ao Māori. The institution of prayer is a fundamental medium by which LDS members are encouraged to counsel with God in all their doings in order to receive guidance, abundance and a relationship with Deity. Karakia is also a medium by which Māori ask the atua/kaitiaki for assurance of a people's wellbeing, and that of the natural environment.

Participants also talked about family relationships suggesting that interactions have more to do with good health than just determining what is in effect problematic with their genes.

> Should we have all those things, then we're also more likely to have good health as well.
>
> (LDS, 2003: 13)

When asked about their responses to predictive or susceptibility genetic testing, LDS participants argued that as Māori and as members of the Mormon church priority was vested in the teaching of fundamental principles held within the church. In the section above I have attempted to capture the key features of these principles and their relationship to LDS members responses to issues relating to genetic testing.

7. Conclusion

This chapter has considered the positions of LDS participants on genetic testing. I have attempted to illustrate how their spiritual beliefs have shaped their responses to human genetics and its potential benefits. For LDS members, the use of genetic testing to breed more perfect human beings was incompatible with their spiritual beliefs.

As they talked about genetic testing, LDS participants raised questions about the role that they as citizens, as Māori, and as members of the Mormon Church may have in determining future policy decisions on genetic testing. Initially, a number of the participants were adamant that they did not wish to participate in the study because they could not see the value in their participation. In contrast, other participants said that, as a result of participating, they were more informed about the possible impact of biotechnologies.

Ultimately, Māori LDS indicated that the Mormon faith would take absolute priority over any decisions they would make whether as individuals or collectively. The members talked about how they aspire to be "creators of worlds in the next life and therefore success for them are more than the accumulation of wealth" (LDS, 2003).

Many of the LDS members perceive genetic testing technology to be a resource for others that can be used to promote human health and well-being, subject to certain conditions, such as informed consent. Nevertheless, they situate themselves in terms of the bigger picture with what really is at stake for them consisting of spiritual salvation for all eternity.

CHAPTER 5
Rongoa Māori scrutinize genetic testing

1. Introduction

The previous chapter highlighted the significance of the spiritual and religious beliefs of participating LDS church members as they reflected on issues relating to genetic testing. It also explored how these beliefs interacted with their use of key tenets of Te Ao Māori and aspects of western science. While Mormon doctrines were defined as most important, church members were seen as drawing on several different knowledge systems as they talked about genetic testing.

This chapter draws on conversation among rongoa practitioners (alternative health healers) whose core business and knowledgeability is located in the practice and utilization of matauranga Māori (traditional understandings of health) that are embedded in knowledge that derives from the realm of kawa tipuna. Grounded within an integrative understanding of the world, these rongoa practitioners articulated their responses to genetic testing within the context of their practice as healers, as Māori, and as consumers of a dominant western worldview on health.

Rongoa practice involves the extraction of healing properties from leaves, twigs, and bark of native flora, as does some non-Māori homeopathy practices. The extracted materials are dispensed in various forms, including liquid, ointment, or capsule. Rongoa involves a holistic approach to health and healing, combined with a commitment to making this health service accessible and affordable to people generally. Like LDS church members, rongoa practitioners gave priority to a particular knowledge system as they talked about genetic testing. However, analysis of the transcript of their conversation also demonstrates that other knowledge systems are also relevant as they reflect on genetic technologies in general and genetic testing in particular.

2. Restoring the Past and Reclaiming a Future

Against the background of a history of suppression, confiscation, and resistance, the rongoa practitioners who participated in this research experienced a deep sense of connection between the colonizing effects of the early 19th and 20th centuries and the disruption of matauranga Māori and traditional healing practices. The Tohunga Suppression Act (1907) (New Zealand Government, 1907) enforced the slow eradication of rongoa knowledge and practice. The enforcement of legislative and policy decisions to outlaw rongoa practice in early New Zealand colonial history contributed to making these healers sceptical about genetic knowledge and the technologies associated with genetic testing and bio banking. This chapter aims to highlight the importance of rongoa Māori as an alternative to western medicine, and to represent the positions of the practitioners who shared some of their deep-rooted concerns about western science. The invitation to talk about genetic testing was taken up as an opportunity to look critically at western science and at genetic modification, which was in the forefront of their consciousness when the focus group interview took place.

The advocacy of traditional health practices grew out of international awareness of local knowledge and the contribution that traditional health systems could make to better health service delivery. In stark contrast to approaches to traditional healing in the colonial past, the National Advisory Committee on Core Health and Disability Services recommended to the Ministry of Health that resources be used to provide traditional healing services. The Committee advocated that:

> Regional Health Authorities purchase aspects of Māori traditional healing, to be provided in conjunction with other primary health services, where there is reason to believe this will improve access to effective services for Māori and lead to better health outcomes.
>
> (National Advisory Committee on Core Health and Disability Support Services, 1999)

The rongoa group that participated in this research draws its funding from initiatives developed in response to that recommendation. It began as a response by others to the challenges put forward by local kuia for the collection of local knowledge of rongoa Māori, histories, and stories of a people who were once active in sustaining a way of life. This was directed at ensuring that the taonga of traditional knowledge could be passed down to future generations. It was recognised that anyone could do this work if they had access to the necessary knowledge:

> And what you were saying we get these treasures that have been left to us. Everybody has visionary skills, everybody could be a matakite if we take time to do it everybody is a healer and we've all healed ourselves it's only when we get specifics.
>
> (Rongoa, 2003)

Within the context of the Māori conceptual principles mentioned above, rongoa practitioners articulated three critical themes pertinent to their view of genetic testing. Firstly, they contrasted two world views - western science and Matauranga Māori - and were critical of the neglect of traditional Māori knowledge. This made them sceptical about genetic science and about genetic medicine. Giving attention to this subject was seen as potentially acceding to a dominant worldview - the ontology of western science. The rongoa practitioners upheld a matauranga Māori worldview in opposition to western science. This often resulted in the practitioners conflating genetic engineering with genetic testing when asked to respond to issues around genetic testing, despite researchers' attempts to articulate the differences. Both genetic testing and genetic engineering were located within the discourse of western science, whose dominance in Aotearoa/New Zealand was problematic for rongoa practitioners.

Secondly, because they found it difficult to distinguish between genetic modification and genetic testing, rongoa practitioners saw genetic testing as a form of knowledge which could be used to interfere with the natural environment and whakapapa and other constituents of Māori ways of life. This was a threat to the field in which they did their healing practice, to their knowledgeability about the natural resources, and to the accessibility of appropriate materials required to carry out traditional healing. Finally, the practitioners expressed ambivalence when faced with the possibility that genetic testing might assist in enhancing the quality of life for mokopuna through identification of susceptibility to certain disorders.

3. Integrative Knowledgeability

Rongoa practitioners' everyday work involves extracting natural materials for health and healing remedies from the whenua (the earth, land) and things that grow in it. The practitioners' knowledgeability stems from the realm of kawai tipuna, and the methods have been passed down from generation to generation:

> [Awhina] We are using the traditions of our tipuna that have used them for centuries before scientists came along and it is still proven to be more effective with what the scientists have to show, so hey...
>
> (Rongoa, 2003)

Generally the practitioners viewed the genetics as something that reduced human beings to their molecular components. The practitioners articulated a strong sense of intergenerational connectedness that involved links between the secular and sacred worlds. They asserted strongly that humans were not just a conglomerate of genes, or DNA, or carbon containing organic molecules. Human potentiality was seen as more than human physiology. At the same time they asserted the practical significance of rongoa knowledge as "archaic knowledge":

> [Whaea] … if you are talking about science, archaic knowledge, that's science and that's traditional archaic knowledge then we use that archaic knowledge which is what you're talking about in matakite. I would rather go to a good matakite that comes through the kumara vine [of] who the good matakite are you know there's no question as to the quality of the information you're going to get. You would not go to one that's really bad but you can't tell with this can you. There's no saying that it is good.
>
> (Rongoa, 2003)

These practitioners articulated an integrative view of the world that was opposed to the reductionist view which they saw as characteristic of western science. Rongoa practitioners do not just use the properties of leaf and bark to heal, they also use karakia to call for divine intervention to ensure the wellbeing of the properties about to be harvested and utilised. The rongoa practitioners focus on networks of relations between people and things, and the relationships between spiritual and physical forces. Their destabilisation of the primary importance of people relative to things mirrors features of actor network theory discussed in Chapter two.

In their concept of the 'Hume machine' Teil & Latour consider "associations" established between humans and non-humans (1995:1). They argue that computers do not have the same capacity to be in the world in the same way that humans do (1995:4). They contend that a "whole network of contingent circumstances is superior to its parts - the skeins or structures that summarize its associations" (ibid). Their position parallels to Māori conceptions of whakapapa where humans are not privileged over non-humans, but are part of an association of heterogeneous components. Haraway endorses this point by arguing "cyborgs are not reverent; they do not re-member the cosmos. They are wary of holism, but needy for connection -they seem to have a natural feel for united front politics, but without the vanguard party" (1991:151).

Traditionally, Māori custom emphasised the notion that people are 'most important of all',[28] yet at the same time, the understanding of who people are is not limited to humans alone, nor are the other contributors to whenua reduced to their utility or monetary value in colonial or global markets.

The practitioners have explicit local knowledge of the natural environment they have learned to utilize since they acquired this knowledge from their ancestors. This has been particularly necessary for the revival of cultural practices that were discarded by early colonization:

> We know our areas that we can go and pick rongoa. We know the lay of our whenua te tika me te pono o te whenua. We also know our climate …it's changing. The changes have an effect on the rongoa and the rakau... If it were to change there would be a whole cycle of relearning… the essence of the mauri within our rakau would change. This would affect the dispensing of our rongoa and what is in our rongoa and how we prescribe our rongoa.
>
> (Rongoa, 2003:6)

The participants articulated a deep sense of responsibility at an individual level and at a wider collective level. The following section gives attention to their understandings of this responsibility – best articulated in Māori as kaitiaki

4. Internalising Responsibility

The practitioners assert their role in the community and among whanau, hapu, and iwi as providers of traditional health care methods and well-being within a holistic framework. They see this as exercising their responsibilities as kaitiaki - those with a responsibility for care of other people and the environment. Whaea expressed it in this way:

> I think we as practitioners and I mean we as whanau, hapu, iwi, should take a responsibility for doing something about this and not the government
>
> (Rongoa, 2003)

[28] Hutia te rito o te harakeke, kei hea te komako e ko. Ki mai koe ki au, he aha te mea nui o te Ao? Maku e ki atu, he tangata, he tangata, he tangata. Pluck the heart from the flax bush and where will the bell bird sing? Ask me what is the most important thing in the world and I will reply it is people, it is people, it is people! (Constructive Conversations/ Kōrero Whakaaetanga utilised this whakatauki, proverb to introduce the topic of genetic testing in focus group interviews).

The concept of kaitiaki also manifests a pragmatic sense of self and, in turn, a sense of responsibility for the natural environment. If the natural environment is cared for, humans will benefit from it and prosper. If it is abused people will not prosper. The notion of kaitiaki is recognized in the New Zealand law books particularly under the Resource Management Act (1991). The Act states that regard must be given to "kaitiaki" and defines this term as 'the ethic of stewardship and efficient use and development of natural and physical resources [in the] use, development, and protection of natural and physical resources" (New Zealand Government, 1991).

The practitioners see genetic science as posing risks for the future of whakapapa and Māori understandings of the world. This encompasses genetic engineering and, by implication, genetic testing:

> …it's [genetic engineering/testing] certainly going to change whakapapa…and I don't want that happening to my children, I want them to have their whakapapa clear from te po, te kore to where we are now.
>
> (Rongoa, 2003)

Practitioners are also acutely aware of the fundamental environmental impact that neo-liberalism and globalization could have on their practice and ultimately their traditional customs.

5. The Interplay and Interconnection of Māori conceptual tools

Rongoa practitioners were concerned about the implications genetic testing could have on whakapapa and a Te Ao Māori:

> [Whaea] It's not a matter of who owns genes. It is [about] understanding the disorders not about the cure of disorders. We don't know what the outcomes are from genetic engineering or from having a biobank. And from that, the information maybe misused into changing whakapapa. …You know I want my children to know, my mokopuna to know their whakapapa, I don't want them to find out a hundred years from now that there was a cow involved in our whakapapa.
>
> (Rongoa, 2003)

Whaea mentions the challenges posed by the use of transgenic technology.[29] Nga Kaihautu (the Māori advisor board to ERMA) and Ngati Wairere (the hapu whose land was being proposed as the site for transgenic research), rejected such these transgenic experiments arguing that they were culturally offensive and had no regard for cultural values or sensitivities. In the same way, the rongoa practitioners expressed their concerns about genetic testing. They found it difficult to disassociate it from genetic modification and said that they saw it as a potential threat to traditional customs and values including the relational connectivity that is referred to as whakapapa. The rongoa practitioners shared similar concerns to those of Ngati Wairere, who were concerned about changing the natural state of the environment through the mixing of genes. Change in the genetic structure of plants and the physical environment is particularly critical for rongoa practitioners who utilize natural resources to gather and collect rongoa. For this reason, the practitioners exercise a firm desire to assert their kaitiaki status over the natural environment to ensure whakapapa is protected for future generations of Māori. Māori do not see the sacred and secular as separated but as parts of the whole (Irwin, 1984: 5).

The practitioners were not convinced that genetic testing would provide knowledge about whakapapa that was useful. They see whakapapa as a focal point of connecting across generations, as a process that includes attention to the natural environment as well as genealogical links between people. They view their role as healers very seriously and this incorporates their role as kaitiaki over the land from which they access their materials.

The participants articulated a pragmatic view on their role as practitioners within the community and within the practice of health. They considered the issue of taking care of one's self, and employed the notion of tino rangatiratanga to assert independence and the need for self care:

> [Whaea] If we're talking about tino rangatiratanga then we must come back to our own selves and get to know our bodies, get to know how we work, not depend on science or doctors to tell us when we're unwell. The wellness and the wholeness of what we are looking at and then we won't have to depend on these [genetic science] because that's how we were…So if I was looking at my breasts and I was

[29] The case Whaea refers to involves transgenic cattle applications for modified cows. Ngati Wairere the hapu whose land these tests were being carried out by PPL Therapeutics, a Scottish biotechnology firm and creators of Dolly the sheep, facilitated a proposal to produce milk that had enhanced nutritive value and might possibly be used as a drug for the treatment of multiple sclerosis. The Environmental Risk Management Authority (ERMA) approved the research after considering the evidence which included the insertion of human genes. Nga Kaihautu, the Māori advisory board to ERMA, dissented and sought to engage in a wider debate with Māori. In its *Report to the Environmental Risk Management Authority*, Ngati Wairere found the mixing of genes between species culturally offensive, claiming it was: "constituting an affront to the mauri inherent in whakapapa" as well as health risks related to physical and metaphysical imbalances where any species had been interfered with "in a manner not consistent with tikanga" (Ngati Wairere, 1999).

in touch…its something that we must try and teach our children to be aware of their own bodies:

(Rongoa: 2003)

The following section discusses in more detail how the ontological worldviews of rongoa practitioners may influence their critical discourse with genetic sciences and technologies.

6. Rongoa Practitioners Articulate Resistance to Genetic Testing

Although the focus group discussion was set up to talk about genetic testing, the rongoa practitioners were most interested in talking about the implications of genetic modification for the plants that they used in rongoa. They also wanted to discuss indigenous rights in flora and fauna. Conflict about rights in indigenous flora and fauna is epitomized in a Waitangi Tribunal claim, entitled WAI 262 (Waitangi Tribunal, 1991). The rongoa practitioners voiced considerable concern about the potential loss of taonga, including native flora and fauna. The Wai 262 claim saw Māori and other indigenous groups around the world oppose such exploitation. The claimants cited:

> actions, omissions and policies of the Crown and its agents [that] led to and continue to prevent Maori exercising kaitiakitanga in relation to the species Pupuharakeke (flax), and are therefore a denial of the te tino rangatatiratanga o te iwi Maori as it applies to indigenous fauna.
>
> (Waitangi Tribunal, 1991)

The claimants further state that the establishment of scientific reserves, protected areas, and other actions or inactions of the Crown which prevent or inhibit Maori access to the species Pupuharakeke, is a denial of the right to maintain those cultural and spiritual concepts which are an inherent part of tino rangatiratanga.

Rongoa were generally sceptical about the value of science for their work:

> [Temepara] I don't see the role of science assisting rongoa. But, if people choose to do …conventional medicines, then I suppose that you could use rongoa and conventional medicine side by side. But, that would be as close as it would get for me. Scientific...We're using the traditions of our tipuna that have used by them for centuries, before scientists came along. It's still proven to be more effective than what scientists have to show…
>
> (Rongoa, 2003)

This position was defended by all participants who argued that for far too long rongoa Māori has been considered a minor alternative to western modes of health treatment when the practice has legitimacy in its own right. At the same time, practitioners also saw there were cases where conventional medical practice is in the best interest of the person requiring treatment. Whilst they acknowledged this, they remained steadfast in exercising the importance of their beliefs and practice.

> Whaea: …you know in some cases it's very difficult for us to stop but we can put in safety measures I'm sure but, I'm totally opposed to it. I've had a heart attack; my whanau is predisposed to heart attacks so it's only natural that that's going to be my fate at the end of the day is a heart attack okay. And it's only, you know, not so many generations ago that we've got all these machines and everything to make us live and its not entirely natural. So if my destiny is that I die at a certain age through a heart attack, I can help myself through my own living and my own exercise, but I don't believe in finding out other ways that I can live until a hundred. It doesn't seem natural to me, in the natural state of the world.
>
> (Rongoa, 2003)

Rongoa practitioners also expressed a deep concern that genetic testing may impact on whakapapa, the fabric that constitutes Māori society.

> The real question is about what will genetic testing do to our whakapapa, the thing that binds us. How would genetic testing affect whakapapa? I mean I'm not just talking about the whakapapa of people because it's all the same. If we were to do genetic testing and I mean of rongoa, which is where we are, if we were to just for example change the genetics of our rakau…
>
> (Rongoa, 2003)

Rongoa practitioners assert whakapapa as the ako, the thing that binds people together to the past, present, and future. This form of binding links to the relational connectedness of a people connected to the natural environment by virtue of the cosmological parents Ranginui me Papatuanuku.[30] Whakapapa is inherent in Māori identity and way of life.

> [Whaea] At the end of the day it is about our whakapapa and predisposing our whakapapa is to determining what will happen to our whakapapa so that's one of the biggest issues for me as well with genetic engineering concerned. You know and the prick test, the prick database has issues and

[30] See Satterfield et al. (2005); Roberts et al (2004), Mead (2003, 2004), Cram (1993), Cram et al. (2000), Cram et al. (2004), Phillips (2005) for further discussion of the symbolic significance of whakapapa.

people know that. (Rongoa, 2003)

The rongoa practitioners perceive genetic testing to be yet another form of western scientific practice that potentially denigrates traditional Māori culture while appearing to be directed at the good for all mankind. The practitioners are confident in their own practice of their own matauranga and their own way of doing things according to the knowledge that has been handed down mai rano.

When asked to consider the parents' dilemma of deciding whether to allow a blood sample to be taken from their child to have a genetic profile established, one participant stated that there are no proven answers to particular diseases including cancer. Whaea indicated that her concerns about genetic testing related to the uncertainty of information about DNA that might have devastating impacts on people's lives. Whaea poignantly backed up her discontent about predisposition testing. She referred to the 'Great Smokies Genovations Test.' (Barrett and Hall, 2003) that offers testing such as DetoxiGenomic Profile to identify SNPs (single nucleotide polymorphisms) associated with detoxification defects related to increased risk for certain cancers, chronic fatigue, multiple chemical sensitivity, and alcoholism. Whaea states:

> There is no case that proves they can predispose the smoking gene... or that they can find that gene that predisposes us to smoking. That would have a major effect on us if we want to claim insurance because you would be dying at this rate. You have this genetic gene that says you're a smoker, predisposed to smoking.
>
> (Rongoa Māori, 2003)

The smoking test according to Barrett and Hall:

> … empowers physicians and patients to realize earlier, more effective preventative interventions---years before disease develops; precise, customized therapies that truly address each individuals needs; and improved clinical insight into patients with treatment-resistant 'chronic' conditions.
>
> (Barrett & Hall, 2003: 2).

Another pressing issue for the practitioners was the utilization of databases to store genetic information. There was a deep sense of distrust amidst the practitioners of processes associated with storing medical information. They saw the use of databases as a tool by which the world could access one's private information. However, at the same time, the practitioners also acknowledged their own unique position of having their own database that is set up for the use of

their practice. Ultimately, the practitioners argued that genetic information would need to be stored in a safe place, that could only be accessed by the individual to whom the information belongs and the person who is delegated the power to collect the information. The practitioners are adamant that there must be a trust factor in order to protect information, particularly in light of potential prejudices and discriminatory regulations that could be imposed and enforced by insurance companies.

Issues related to predisposition testing encouraged talk among the practitioners about how in traditional Māori society, tohunga often mapped peoples lives through whakapapa and how an individuals status was considered within the hapu. The location of individuals was often pre-determined according to their birth order or genealogy or by the status bestowed upon them by a Tohunga, or Ariki, as Whaea articulates,

> …If we're looking at whakapapa people will say, well you map out the lives of your children anyway because that's what we did traditionally. We, from womb to tomb said right here is a healer ... that person is going to be nurtured. So there are some mappings that are part of our society and it's for the betterment of the society because at the moment we are saying mapping that we need more lawyers or we need more doctors so we're encouraging our children. I mean we are taking it upon ourselves and our whanau to say right you know you, your going to be a doctor your going to be a lawyer and you feed the children he kai korero he kai tika so you feed them that kai they will be that. We know that so it is different to what were saying mapping out a life here. It's the consequences at the end that make the difference.
>
> (Rongoa, 2003: 4-5)

This suggests that 'mapping' is a part of traditional Māori knowledge and practice, but not on the basis of genetics or DNA applicability. Rongoa practitioners considered that susceptibility testing could create a whole new set of problems if others could access knowledge associated with your genetic makeup.

> [Whaea] I mean we see the most powerful tool is our mind isn't it? So if we have a mindset that we are going to be predisposed to, if our mind tells us that it's going to happen the same as we can use our minds productively we can also use them negatively.
>
> (Rongoa, 2003)

7. Exercising Mana Motuhake

According to Emirbayer & Mische: 'As actors respond to changing environments, [they] must continually reconstruct their view of the past in an attempt to understand the causal conditioning of the emergent present, while using this understanding to control and shape their responses in the arising future (1998:969). The rongoa practitioners, like Emirbayer and Mische's abstract social actors, reconstruct their views of the past as a resource for understanding their ever transforming present. They exercised their agency as Māori traditional healers by resisting the assumed advantages of genetic science. It could be argued that the positions adopted by rongoa practitioners were the outcome of a long history of colonial rule and political resistance[31] which included the Tohunga Suppression Act and the Native Land Acts as well as the New Zealand Land Wars (Belich, 1996; King, 2003).

With this in mind, the participants' conversations in some instances focused on their own agendas which sometimes involved resistance to any discussion about genetic testing. This resistance was an outcome of the history of western science and its role as a component of colonization for Māori. For the rongoa practitioners, genetic testing is associated with another threat in a long line of threats to indigenous knowledge.

Other participants from the rongoa group suggested the research materials needed to be more relevant to a Māori audience and involve the use of simpler methods to elicit talk among research participants. They suggested books or videos by way of examples:

> [Awhina] It [the contact group interview] gave me an insight just where things were going. I'm a wee bit like Mihi, probably look at a little bit more resources, more simplistic type resources that are easy to understand quick and probably run through them before the questionnaires to help for answers and conclusions I suppose
>
> (Ronoga: 2003).

Whaea also added:

> I like the process that we don't know what we're in for, but it's not for me to talk about koha but a koha back to the participants that there might be, and I know that there's going to be a research at the end of the day, there's some really good books out on genetic

[31] For instance, colonial troops invaded Parihaka in 1881, where Maori were engaged in passive resistance against the confiscation of their lands. Men of Parihaka were killed, imprisoned, or relocated to the caves of Dunedin and the settlement was looted and destroyed in the following weeks (Riseborough, 2002).

> engineering and I'm not saying for us but I'm saying for other groups that the Whanganui law forum have put out but it might be a good idea to leave something like that as a koha to people.
>
> (Rongoa, 2003).

Participants also spoke about the advantages of coming to the topic fresh without what they referred to as 'prior knowledge':

> I think it was wonderful and some of the feedback it was pretty amazing to hear from them. And that might have been spoilt when you have prior knowledge you know when you have rangahau [research] sometimes prior knowledge spoils spontaneity and it was just wonderful to hear, and also for you Wiki its all part of your growth so it was really neat really important that you should be here as well.
>
> (Rongoa, 2003).

Some people used the opportunity at the end of the session to reflect in general on the topic and argued that knowledge about human genetics might lead everyone to living longer and contributing to overpopulation:

> [Awhina] We don't but then I guess that's our life's destiny. If we were to all find out I guess what we were going to die of and try and make ourselves live another hundred years longer or 50 years longer then we're gonna be even more overpopulated then what we already are. It's a bit like the animal world. Its give and take, you know one lives, one dies for another to live. And it's the same sought of thing we're only human but we're still mammal or animal and some will get diseases early and some won't. And some die early and some don't but when one dies another is born, so it's still the same process.
>
> (Rongoa, 2003)

Overall, there was concern abut the possible impact of replacing the Guthrie test[32] with forms of genetic profiling. One participant said that:

> [Temaria:] I would have a lot of issues as to the mapping out of your child's life. What are the natural things they will learn? They will grow up knowing bits are already pre mapped out, predisposed for them? And, then they won't get insurance, bank loans, no mortgages no jobs if there is anything wrong with that child. I think it should be that they grow up natural, traditional environment and I'd have to worry about whakapapa.
>
> (Rongoa, 2003)

[32] The Guthrie test involves taking blood samples from newborn babies for long-term storage.

For rongoa practitioners, examining DNA and attaching importance to it as a key determinant of human health is an example of reductionist science. Their focus is more holistic and involves attentiveness to a variety of factors that promote human health which include tika relationships between people and things. Rongoa practitioners explicitly operate within a different discourse which they defend as a means of understanding the physical, spiritual and environmental welfare of their patients. At the same time they recognise that many Māori who use rongoa also use western medicine as well:

> [Awhina] I suppose it is a part of tino rangatiratanga but it is really just a part of who we are as people. I don't see the role [of science] as assisting but as it stands today if people choose to do conventional medicines then, you could use rongoa and conventional medicine side by side. But that would be as close as it would get for me...
>
> (Rongoa, 2003)

8. Conclusion: Reclamation of Matauranga Māori over Genetic Testing

This chapter has presented the responses of a group of rongoa Māori practitioners to some issues relating to genetic testing. At the same time, I have acknowledged the tendency for them to resist talking about genetic testing and to focus on genetic engineering rather than testing. The main focus of conversation for rongoa practitioners was their reclamation of their matauranga, natural resources for their rongoa practice and mana motuhake. This right to practice and the knowledge they valued was once declared illegal (Salmond, 1997). For rongoa practitioners, genetic testing is a manifestation of western science couched within a reductionist framework. Through the resourcefulness of rongoa practitioners, rongoa Māori continues to thrive and be acknowledged amongst Māori and non-Māori alike.

Central to the kaupapa of the rongoa practitioners who participated in this study is a sense of pride and dignity. This is based on their providing of traditional health care in respect to rongoa Maori, which involves provision of rongoa rakau, mirimiri, manaaki, and counselling in their region. Their approach to genetic testing and their criticism of it are shaped by their political location as traditional health providers and their knowledge of rongoa. Like the LDS group, they are sceptical about the benefits of testing, but for quite different reasons. This arises out of their location in different knowledge systems and their goal – the recovery of Matauranga Māori.

According to the rongoa participants, genetic testing is yet another form of colonisation by which

the non-Māori continue to force a disempowering knowledge on those who seek to develop and extend different knowledge systems. Whilst participants refused to access the service for themselves, they associated genetic testing with increased potential for human longevity. This led them to express concern at the over population of the planet and how that might impact on the future of Aotearoa.

The rongoa practitioners were dedicated advocates of empowerment for Māori. They argued that they should take responsibility for their own situatedness and futures.

> [Whaea] I actually think we have a responsibility as whanau, hapu and iwi to empower our people with knowledge of genetic engineering. It's for us to do that; we don't have to depend on the doctors and the like. I just think we have to take responsibility ourselves, that's what tino rangatiratanga is not about giving it over to other people but your own whanau. And your whanau might be just a collective of women like ma wahine kaitiaki o te ao, that's your whanau who go round take that responsibility. We have about 3 women here that have taken that responsibility take it out onto marae, take it out into the community what it actually is the biodiversity, genetic engineering so that they know all the differences.
>
> (Rongoa, 2003)

I have argued that rongoa practitioners respond to genetic testing in particular ways because they are interested in raising the status of an ontology and epistemology that has been largely subjected under a different system. The rongoa practitioners' made assertions about traditional knowledge through the use of Māori conceptual tools, including whakapapa, kaitiaki, mauri, and mana motuhake as values and principles they apply in their practice. The practitioners 'inhabit' a way of knowing that has been passed down through the generations from the kawai tipuna (Clarke, 2004, Marsden, 1975. They demonstrate deep-rooted sense of responsibility (kaitiaki) as they work with resources in the natural environment to pursue well-being and good health.

For the rongoa practitioners, genetic testing is another way of devaluing their knowledge and their struggle to have rongoa Māori entrenched and recognized as a legitimate approach to health practice in its own right, not just as an alternative to scientific medicine. They do acknowledge the role of the Treaty of Waitangi as a potential lever for Māori involvement at all levels of decision making. However, their primary concern is with the grass roots communities and they assert this by being unrepentant in advocating their practice and knowledgeability.

> We've been very sure and clear that we've maintained tino rangatiratanga in what we're doing.
>
> (Rongoa, 2003)

The following chapter considers responses from Māori law practitioners who articulated their concerns about genetic science in relation to their knowledge of New Zealand jurisprudence and the Treaty of Waitangi.

CHAPTER 6
Māori Lawyers Evaluate Genetic Testing

1. Introduction

This chapter discusses how a group of Māori lawyers in Wellington, New Zealand's capital city, talked about genetic testing and biobanking. These lawyers' geographic location is significant because New Zealand's major legislative and administrative work is done in this environment, and it is a centre for several major businesses and financial institutions. This is also a city with a high concentration of Māori professionals (Census NZ: 2001: Snapshot 4 Table 11) and those with post-school educational qualifications. Māori residents in Wellington have the highest levels of educational attainment in New Zealand (Te Puni Kokiri 2001b: 108) and are increasingly employed in work that requires professional skills.

The lawyers who participated in this study occupy a place at the interface of a western educational and legal system and Māori social worlds and conceptual tools. This chapter illustrates how they negotiate between these different systems/worlds/tools as they consider the implications of genetic testing and biobanking. Just as Stephen Robertson and the Māori Whanau had to negotiate the ontologies of western science and tikanga Māori, so these lawyers have to negotiate the relationship between a legal system that attends to individual rights and the collective understanding of whakapapa that is at the core of Māori ontology. The lawyers attend to the need for formal regulation of science and technology while also giving due weight to holistic Māori concepts like mauri.

A discussion of their negotiation of the interface between these ontologies is preceded by a brief overview of the education and legal system in New Zealand post colonisation. Reflection on the interface of a western education system and Māori social worlds is central to understanding how these lawyers constantly negotiate the relationships between science, the legal system and matauranga Māori. This is the context for consideration of three key themes that were

identifiable in the transcript of the focus group interview with the three Māori lawyers who participated in this study.

The first theme involves attention to the positive and negative impacts of genetic testing at an individual and collective level. This focuses on aspects of the lawyers' talk about the relevance of the Treaty as they reflected on the potential collective benefits and risks of genetic testing to whanau, hapu and iwi.

The second theme connects to some of the contradictions and dilemmas the lawyers articulated concerning the protection of whakapapa for future generations and science as a mechanism that potentially disrupts cultural values. Throughout their conversation the lawyers considered that the Treaty of Waitangi provides a basis from which Māori can assert their agency, mana motuhake autonomy and rangatiratanga.

The third theme addresses issues relating to the protection of information and avoidance of discrimination. I will consider how this group of lawyers talked about the need to control information about individuals, hapu and iwi and the Treaty as a form of leverage for both individuals and collectivities.

As Māori professionals with kinship ties to diverse whanau, hapu and iwi, these research participants had obtained a tertiary education and were located within one of the oldest European professions imported to Aotearoa/New Zealand from Britain in the early 19th century (King, 2003; Walker, 1999; Sinclair, 1997). It could be argued that their integration of the profession of law and Māori cultural values is an example of what Kuhn refers to as 'commensurability' (Kuhn, 1962). Two of these participants are young lawyers embarking on their professional careers within the Wellington region. The more mature lawyer who participated in this discussion works for a government department. He drew on both his professional knowledge about his profession as well as his personal health experiences during the focus group interview. The contributions of all three lawyers illustrate their attempts to integrate understandings of the legal system in Aotearoa/New Zealand and tikanga Māori.

The following section considers the ontological resources that these Māori lawyers used to shape their response to issues relating to genetic testing.

2. The Treaty of Waitangi and New Zealand law

New Zealand law has its origins in British legislature and common law (Greville, 2004). English constitutional conventions, or principles, that constitute legal frameworks, were applied in New Zealand by January 1840 (ibid). On February 6th 1840 New Zealand was declared a sovereign state by Governor Hobson following the signing of the Treaty of Waitangi by some Māori chiefs and British representatives. Since that time, there has been significant controversy about the relationship between British/New Zealand legal frameworks and the Treaty, particularly about the extent to which it provided Māori with specific rights and protections. This has included the position that, unless legislation made explicit reference to the Treaty, Treaty rights would be unenforceable (Orange, 1987). In this regard, in 1877 Prendergast CJ ruled 'the Treaty is a simple nullity' (see Wi Parata v Bishop of Wellington [1877] 3 NZ Jur (NS) 72; Te Puni Kokiri: 2001a: 43). In the last 30 years, since the Treaty of Waitangi Act 1975, the Treaty has had a much more significant status in New Zealand law and Government but as yet has no constitutional status (Joseph, 2001).

Article 2 of the Treaty includes protection over taonga. Taonga is inclusive of customary practices (Orange, 1987). Māori were granted citizenship rights, while at the same time conferring on the Crown the right to govern in the interests of all New Zealanders. Treaty relationships between the Government and Māori are ongoing and dynamic and have been since 1840. The New Zealand Court's approach to the Treaty today is expressly referred to in statute where the courts are obliged to give effect to its reference (see NZ Māori Council v AG [1987] 1. NZLR 641; Joseph, 2001; Orange 1987)

Treaty rights can be heard in New Zealand courts under the auspices of the Waitangi Tribunal which provides a forum for hearing historical and contemporary grievances regarding breaches of the Treaty subject to the Treaty of Waitangi Act 1975. It can recommend action to Government, but its conclusions are not binding. Sorrenson noted in an essay on the role of the Waitangi Tribunal: 'Because of the determined efforts of the Māori people to resist assimilation and preserve their identity, the Treaty has become the basis ... for the coexistence of two peoples within one nation' (1989:159).

In the 1970s, Kōhanga Reo Māori immersion pre-schools were established to educate Māori

children in Te Reo Māori. Kura Kaupapa Māori schools at the primary level were established as extensions of Kōhanga and eventually, three whare wananga, Raukawa, Aotearoa and Te Awanuiarangi, were established at the tertiary level. These whare wananga were developed in parallel to tertiary institutions with an emphasis on affecting the future of Māori in New Zealand.

All of the lawyers who participated in this contact group discussion were trained as lawyers after the passing of the Treaty of Waitangi Act in 1975, the emergence of Kōhanga Reo and what is often referred to as 'the Māori Renaissance'. Their education as lawyers occurred in a time when the Treaty of Waitangi was increasingly recognised as a document that had implications for policy, regulation and practice in relations between Māori and non-Māori.

3. The Potential Benefits of Genetic Testing

Emirbayer & Mische (1998) articulate a theoretical approach to agency that "reconceptualises human agency as a temporally embedded process of social engagement informed by the past…but also oriented to the future…and toward the present" (1998:963). This means that actors, in this case Māori law practitioners, resolve potential complexities that new knowledge, such as genetic testing may impose on their lives by reconstructing their everyday life experience. This potentially leads to a transformation of values and themselves. This is evident in the lawyers' initial reaction to issues concerning genetic profiling and predictive testing. The lawyers began to assess the potential advantages of genetic science for Māori. They argued that the information surrounding genetic tests needed to be considered in its totality and not in isolation of other factors such as social, cultural and ethical. They also thought that preventative measures directed at avoiding potential genetic disease were more advantageous than waiting for cures for genetic conditions. Tara asserted this in the following way:

> I think it's [genetic testing] is a benefit. I think you can't look at it in isolation though. I wouldn't say it's a significant benefit and then just leave it at that, because there are significant disadvantages and it's about balancing those advantages and disadvantages with benefits and non-benefits. I would definitely say that it is [a benefit] especially for things where, prevention is always better than trying to find a cure. If it is something where you get treatment for early or they can get help rather than falling through the cracks and never know would be better.
>
> (Lawyers, 2004)

Tara's assessment is similar to the discourse surrounding the case of geneticist Dr Robertson and the Māori whanau considered in Chapter one. With so many deaths of their male babies and no previous medical explanations except for the idea that the family could be the recipients of a makutu, the genetic discovery came as a relief for whanau members who now have a scientific explanation for the deaths of these children. This explanation has provided opportunities for particular members to avoid these outcomes in the next generation.

However, Hohepa, the only male participant in the lawyers group, argued for the advantages of genetic testing from a clinical perspective, suggesting that the knowledge attained from the tests could provide information that would be a resource for future generations:

> My arguments for it [genetic tests] are clinical. The information is put onto a shelf, filed and it's always there just in case you want to know the debates. That [genetic information] can tell you your Whakapapa, it's there for history too...
>
> (Lawyers, 2004)

The position adopted by these lawyers contrasts with the rongoa practitioners' concerns for the protection of whakapapa and their notions about authenticity and agency. The lawyers were more attracted to genetic testing as a resource for knowing about your individual predispositions for particular conditions and were more likely to think that genetic profiling might have tangible long term benefits. Hohepa also suggested that particular emphasis on Māori conceptual tools including mauri and wairua may limit the value of attaining new technological benefits:

> There is a wairua issue that we have to overcome to fully appreciate that biotechnology, G.M. (genetic modification) stuff; will it actually assist me in the future? The only way I can recommend it is to get more Māori in there who can explain it to us in our language. This is what's happening here, it's not our language.
>
> (Lawyers, 2004)

Hohepa's statement about overcoming 'wairua' to appreciate the value of genetic biotechnology contradicts the assertions made by the rongoa group who were much more sceptical about the value for Māori of genetic technologies in general and genetic testing in particular. Hohepa is positive about Māori acting as 'translators' of genetic science for other Māori. The rongoa practitioners on the other hand, aim to protect and preserve traditional knowledge that can be accessible and available to other Māori. They are also clear that their practice is not about disseminating knowledge of western science among Māori.

Another Māori law participant, Mere, who was also a science graduate, was positive about the developments in genetic science and medicine. She suggested that human genetics could eventually lead to the eradication of 'bad' genes and improvements in human health:

> From perhaps a purely scientific point of view, or maybe my science side speaking, I would say that it does have it's benefits and perhaps at that time, in 2013, they may be able to bang out that bad gene and insert a new one or they would have all sorts of technologies available to them, but I don't think it's just an easy "yes" answer …There also has to be that element of control.
>
> (Lawyers, 2004)

While positive about the potential benefits of "knocking out the bad gene", Mere emphasised the importance of control over the use of these technologies, even if their offer positive benefits. Mere's comments about the need for control over the application of genetic tests were developed by Hohepa:

> … who is going to control the information? For me, I don't want anyone controlling my life or my children's life or my mokopuna's life or anyone else's life…I just want to say that from a Māori perspective that I think I would be really concerned for those issues only. As I said, the other one is that if people have got diseases, well probably you could find a cure, I don't know, but we need to be in control of those processes that's all. So it doesn't start interfering in who we are and what we are.
>
> (Lawyers, 2004)

While Hohepa reflected on the need for control, Mere responded with a focus on the need to balance the positive and negative consequences of genetic testing. She posed the question:

> Is the potential for benefit greater than the potential for harm?
>
> (Lawyers, 2004)

In this regard the lawyers who participated in this study both recognised the advantages for people generally, and Māori in particular of using new knowledge available through genetic medicine. At the same time, they were also deeply concerned about control over the processes in which Māori might participate and also convinced that there would be negative as well as positive consequences. The need to balance positive and negative outcomes and for control were

key themes in their responses.

4. The Problematic Features of Genetic testing

While lawyers participating in this study reflected on the advances of genetic testing as a way of avoiding potential genetic diseases, they also considered that the benefits of genetic testing are dependent on the protection of personal information and control of how that knowledge is disseminated.

The lawyers talked about the possibility that individuals could be severely disadvantaged if strict ethical procedures were not applied to the control of information about their genetic material. They were particularly concerned about the need for control by individuals and collectivities with respect to how genetic information might be stored and when and how it might be used. Issues concerning confidentiality and privacy were discussed in relation to the storage of genetic material. Mere alluded to the challenging aspects that the process of genetic testing could have on people's lives:

> It [genetic testing] is a benefit as long as you have ultimate control over who that information goes out to… I think control of the information and making sure that's secure would be high on my list of things that I want to have or want to know.
>
> (Lawyers, 2004)

They also extended this concern to personal choices people might have to make in the future if genetic testing was required in order to access particular services, including, life insurance. Discussion in the group focused on the possibility that, if genetic testing was normalised, people would not be able to choose whether or not to be tested. They were concerned about testing not being a choice and potentially being something you had to do.

> Tara: If there is a point in the future where people can have a choice to have their genes mapped out or not, those who don't choose to have it done will be disadvantaged in some way because it will be preferential for people who have it mapped out. It could be a prerequisite of acquiring insurance and it won't be your choice.
>
> (Lawyers, 2004)

The only male lawyer in the group expressed his distrust in the medical profession which was based on a particular inaccurate diagnosis:

> My personal view is I lost faith in that kind of science when they diagnosed me. When they tell you that you are going to die and they give you 5 years, you actually believe it, because you do. It's just the way you are… when I went back they said "oh sorry mate we made this mistake, you've still got the disease, but this is what's going to happen" so it actually destroyed 5 years of my life. That relationship that we had with our children, we were concentrating on surviving.
>
> (Lawyers, 2004)

The lawyers were also concerned that the genetic profiling of new born babies might lead to compartmentalising children if they are shown to be prone to developing a genetic disorder. Their concern was not only about discrimination, but also about the impact of a child knowing about their genetic predisposition to develop certain conditions. Tara stated that:

> If you tell a child that they have got a predisposition for some kind of illness, genetic disorder, diabetes, what kind of effect does that have on them as they grow up? You are compartmentalising them, saying they won't be able to do some things at some point in the future as this genetic disorder rears its head.
>
> (Lawyers, 2004)

5. Genetic Profiling, Biobanking and the Treaty of Waitangi

While positive about the potential benefits of genetic testing, these participants also explored the ways in which acquiring knowledge of a child's genetic profile could be more harmful than not knowing. They argued that looking at someone in terms of their genes could lead to an emphasis on their genetic makeup at the expanse of other aspects of their lives and the social, environmental and economic conditions that might affect their well-being. Mere sympathised with the position of the mother in the hypothetical story who was concerned about the implications of genetic profiling and felt more comfortable about the option of allowing the child to develop as a normal child without having their blueprint or genetic profile 'mapped out'. Hohepa stated that there were severe consequences attached to knowing about your genetic profile.

On the other hand, Hohepa favoured the use of genetic testing as a tool of diagnosis because he thought it should be used to find out what was wrong when people were not well:

> [Hohepa] I would like to know everything about my child even if they were 20 and they were dying. I would like to know everything about that person and why it happened. Is it a degenerative disease? Where did they get it from and how come? I would like to know as much as I can. I need that healing too that comes to that healing process for me. But for them to die and not know that would be terrible. This is where the conflict comes, because you won't know unless they take a little bit of switching.
>
> (Lawyers, 2004)

When participants were asked to assess the potential benefits of genetic testing, their responses were direct and straight forward. Mere argued that, if genetic testing was to be expanded as a way of accessing information about human health, there needed to be strategies to ensure the safeguarding of information about individuals' DNA. She further articulated the crucial role of the Treaty of Waitangi that affords protection to Māori subject to its Article II, in conjunction with the Treaty of Waitangi Act (1975):

> We have to have control over genetic testing and I think that is where the Treaty partnership really comes into play in terms of protection afforded to Māori under the Act. And hopefully where the government will be going or where there is something like this that has implications for Māori or indigenous fauna/flora, even perhaps implications not just genetic but they are pushed over into the area of social/cultural things that we were talking about before.
>
> (Lawyers, 2004)

Upon considering issues regarding the bio bank scenario, participants examined the mock pamphlet with information about a hypothetical biobank and posed many critical questions about this as a possible initiative for the storage genetic data and its use for research purposes. Mere questioned the validity of the information and the promises that were being made to prospective consumers:

> … I looked at this [and] I would say, where am I on this picture? …but bio-bank stands out as not the best way of doing [storage of genetic data] it just says "sell your genetic material.[33]
>
> (Lawyers, 2004)

[33] The pamphlet did not indicate that those providing a blood sample for the biobank would be paid, but it did indicate that public and private research companies would have access to the data.

The participants dissected the statements made to potential donors of blood samples in the bio bank pamphlet. Hohepa stressed that the advertisement was contradictory in that it offered absolute confidentiality whilst simultaneously claiming to be in alliance with academic researchers, crown research institutes and pharmaceutical companies whom he suspected would utilise the genetic material and medical records available in the bio bank to develop new diagnostic strategies, drugs and. genetic tests that they would market. Tara agreed and stated:

> I look at it [bio bank pamphlet] as another form of exploitation. Commercial companies having access to information that you don't, so they can develop a drug that will fix whatever, that you can pay hundreds of thousands of dollars [for], and somewhere down the line you provided the material for them to actually do this.
>
> (Lawyers, 2004)

These lawyers suggested that, if they chose to utilise genetic testing technology, they would weigh their decisions very carefully and take into account the Treaty of Waitangi. Hohepa stated:

> I would find it very difficult to sell it to our people and I probably wouldn't have anything to do with it. If I'm going to have anything to do with it, it would most likely be at a Treaty relationship level where I ensure that I have control of all the documents we have and make sure that it doesn't interfere with anything Māori.
>
> (Lawyers, 2004)

In this respect the lawyers who participated in this focus group discussion were operating at the interface of Māori and non-Māori constructions of decision-making. The lawyers were more positive about using developments in human genetics, but frequently invoked the rights of Māori under the Treaty as forms of collective protection in a field that involves balancing costs and benefits. Agency and empowerment for Māori with respect to genetic testing involves considering how the Treaty can be used to maximise control over the processes and the use of information arising out of testing. This is a case where mana motuhake is asserted and the Treaty is seen as a resource for individuals, whanau, hapu and iwi. The lawyers constantly stressed the need for people to have control of the processes associated with genetic testing and how information arising out of it is used by themselves and others.

6. Protection of genetic information – exercising control

The Māori lawyers who talked about the social, cultural, ethical and spiritual implications of genetic testing had a strong commitment to the need for people to control information about their own bodies and the whakapapa of their whanau and hapu.

Mere stated:

> If it was me, I would want to have the ability to take the test and all those [test] results given back to me. I can have the decision [of] whether to burn it [or] to destroy that information so it isn't kept in the public record…Then that empowers people to deal with it how they want to deal with it.
>
> (Lawyers, 2004)

A key question asked by the lawyers was: 'Will my information be kept safe?' As Hohepa read the pamphlet he stated: "It says no one would be identified. But, who would have access to the biobank?"

The lawyers considered alternative strategies for ensuring the protection of genetic information. Hohepa drew on the principle of kaitiaki as an example of how as lawyers they have an obligation and responsibility to ensure the processes of genetic testing are scrutinised and that the processes applied within the framework do not compromise Māori knowledge and understandings:

> … [G]enetic testing…we should be more involved in it. We should be able to, like scrutinize [genetic testing], because that is our role as kaitiaki of our people. We've got to think is it going to ensure that it's got nothing that's going to cut across Tikanga Maori and things that we believe in. As long as they're not cutting across [and] that they're only testing …
>
> (Lawyers, 2004)

Whilst NZ Genetic Services have detailed ethical guidelines to ensure the protection of genetic information, the lawyers were very sceptical about how these protections have been carried out. This arose out of Māori and indigenous peoples' experiences in the past with respect to the use of research information. The National Geographic project, for instance, is drawing on indigenous peoples worldwide to contribute to a world-wide study that will collect tissue and mouth swab samples from indigenous peoples which will be used as part of a project on human evolution and migration (National Human Genome Research Institute, 2005).

The lawyers were keen to identify strategies that Māori could use to ensure control over their DNA. Crucial as a source of leverage and power was the Treaty of Waitangi. Mere argued that:

> We have to have control over it and I think that's where the Treaty partnership really comes into play in terms of that protection afforded to Maori under the Act … where there is something like this [genetic testing] that has implications for Māori or indigenous fauna/flora, even perhaps implications not just genetic but they are pushed over into the area of social/cultural things …
>
> (Lawyers, 2004)

The Treaty was evoked as a way in which democratic participation in decision-making by Māori could be implemented with respect to genetic testing. Māori participation was asserted in the following way:

> Maori need to be actively participating at the decision-making level, because that's how it should be. I think that's where it comes down to in terms of Treaty jurisprudence, cultural evidence …
>
> (Lawyers, 2004)

The participants considered that the Treaty laid the basis for Māori as partners in decision-making about genetic testing. The partnership identified in the Treaty acknowledges and supports safety and protection measures over taonga as directed in Article II. Taonga implies the concept of treasures which extend to the protection of genes since genetic material is significant for Māori. The lawyers argue for a more participatory role for Māori as a way of implementing full democratic practices in New Zealand society.

As previously considered in Chapter 2, Foucault's concept of power is linked to idea that the power operates through the agency of people. In regard to the notion of genetic testing and the position of the lawyers in this discussion there are connections to Foucault's interest in the body as determined by an interest in "how 'power' is exercised over the body, both by individuals who have internalized conceptions of the "normal" and by governments who collect information on bodies and devise new ways of regulating, disciplining, and routinizing them" (Smart, 1983:80). In this light, Foucault's reflections on power/knowledge can be understood as specialized manifestations of governmentality within institutions or power structures including law,

medicine, universities and even insurance companies. In this regard, the lawyers were very clear about the pitfalls associated with genetic testing and the need for ownership of genetic material:

> Mere: You wouldn't want it getting into the hands of an insurance company where they could dictate whether they are going to cover you in the future for those dispositions that you may have towards a disease…The ownership of the information rests either with the individual or perhaps with the whanau group, not with the state, or the government or the health professionals. Once they have done the tests, mapped it out, what ever they are going to do, all the results and everything, even the materials perhaps that they took, if that's the wishes of the individual gets returned.
>
> (Lawyers, 2004)

7. Individual and Collective Responsibility

The law practitioners have been educated with a western education system characterised by attention to individual rights and individualistic legal conventions that are applied to land tenure, property, ownership and power. This knowledgeability is in tension with Māori ontologies and epistemologies that exist within a collective discourse of whanau, hapu and iwi. Hohepa reflected on the relevance of his Māori identity for discussion of genetic testing by asserting the following:

> Hohepa: As a Māori person, I look at everything that I do with my children (whether it's in the foetus or otherwise) as being part of who I am and who my people are.
>
> (Lawyers, 2004)

The Māori lawyers who participated in this focus group asserted mana motuhake in relation to their connectedness to the land and to their whanau, hapu and iwi. They assert a strong sense of self and identity that is also collective.

At one point in the discussion it was suggested that the future of gene technology could intensify individualism in Aotearoa New Zealand. The lawyers considered that intensifying the power and control of the individuals could also lead to fragmentation of social bonds. According to Tara:

> It would be an act to individualize society even more rather than from this idea of society collective, could perhaps even fragment society and people would focus on the individual even more than they do today. It may be a concern in terms of Māori philosophy, in terms of the collective ownership of whakapapa and things like that. (Lawyers, 2004)

While educated within a legal system that emphasises individual rights, the lawyers who participated in this study looked at the importance of collective orientations to the ownership and control of genes and genetic data.

Participants also expressed concern around the uncertainty of processes that would safeguard the privacy of individuals' genetic information. Tara states that the individualisation of genetic information could lead to genetic tests becoming compulsory. Failure to carry out a test would suggest the individual or individuals have something to hide.

> Tara: It could also, in other ways, change the society dynamics in terms of, if there is that information out there about all of these individuals, and probably some organizations who have access to it, how would society deal with the access issues – not on an individual level, but in a wider group? What are they doing with it?
>
> (Lawyers, 2004)

The lawyers participating in the discussion expressed concerns around collective ownership, particularly with regard to Māori assertions of communal ownership of genes by whanau, hapu and iwi. Mere claims the following:

> I think it [genetic testing] would have implications for anything. Yeah, the whole collective ownership thing. If you get your geno printed out and you get your little laminated geno, you'd say, "that's my Whakapapa". It's perhaps further individualizing everything it and severing it from that communal ownership link with the spiritual dynamic.
>
> (Lawyers, 2004)

The lawyers affirmed the notion of mana motuhake and the use of the Treaty of Waitangi as leverage for negotiating Māori customary rights. The lawyers argue, with conviction, that the Treaty can safeguard and protect Māori interests as afforded to Māori under Article II.

> Mere: We have to have control over it [genetic testing] and I think that is where the Treaty partnership really comes into play in terms of that protection afforded to Māori under the Act.
>
> (Lawyers, 2004)

The Treaty of Waitangi is New Zealand's first official document and can be considered as New Zealand's first act of talking together/commensurability. Hohepa spoke about the importance of straddling of two worlds that are constantly being redefined and reinterpreted. He saw the young

lawyers in the focus group as examples of people who did this and people who had a collective responsibility to engage with and communicate about both worlds:

> We need clever people like these young people coming in because they can live two worlds and some of our people can't. Then we understand the dynamics as in the changing world. For those of us are already fixated in our beliefs:
>
> (Lawyers, 2004)

As the older member in the group, Hohepa acknowledged the evolving nature of education and knowledge in an ever changing climate of values, principles and ideologies.

8. Conclusion

This group's response to issues about genetic testing focused on the use of the Treaty of Waitangi as a lever to empower and promote Māori aspirations and engagement with genetic testing. Some of the participants stated that they would use genetic testing if they wanted specific genetic information, but they were concerned about who would access that information, where it would end up, and how they would have control over it. They considered that information arising out of genetic testing could not be understood in isolation from other factors including, social, environmental and cultural determinants of human well-being. They were concerned about people just being defined in terms of their DNA and about requirements in the future to provide information about your genetic makeup in order to access certain services, especially insurance. The participants further stipulated that they are open to pragmatic solutions, but are cautious about the overall personal, cultural and ethical costs of genetic testing.

The biobank scenario, particularly the hypothetical pamphlet, generated a negative response. They were concerned about the involvement of private biotech companies and the pharmaceutical industry and the possibility of samples of blood and other tissue being used for commercial ventures. The inclusion of a statement that general practitioners would have access to the information was highly controversial for the lawyers participating in this study. They concluded that they would not participate in such a research project should the opportunity arise.

Generally, the lawyers argued that unless genetic testing is explicitly regulated there is a real risk of inappropriate, unnecessary or even dangerous outcomes. This would include medication in

response to poorly understood genetic tests. Given the complexities of such testing, the lawyers in this focus group were critical of the lack of explicit legal frameworks to govern genetic testing in New Zealand.

The following chapter will explore points of convergence among the three focus groups whose responses to issues relating to genetic testing and biobanking have been considered. I will also consider the points of difference that highlight the three groups' distinctive approaches to discussion about the implications of the use of these technologies.

CHAPTER 7
Embracing Complexity of Diversity

1. Introduction

This thesis began with the interaction between a geneticist and a Māori whanau with a unique genetic disorder setting the platform for a wider discussion on genetic testing within the context of matauranga Māori and other knowledge systems. Specifically, I have focused on how Māori of distinct hapu and iwi, located in three distinct knowledge communities; religion, health and law have strategically used the competing, and sometimes overlapping, paradigms of contemporary genetic science and matauranga Māori as they have responded to issues relating to genetic testing and biobanking. Through the 'casing' (Ragin, 1992) of talk among LDS church members, rongoa practitioners and lawyers, I have sought to produce knowledge about how differently placed social actors encounter issues relating to human genetics and its place in Aotearoa New Zealand.

Discussion of these Māori participants' responses has focused on the interface of Te Ao Māori and western science. For example, in the last three chapters each group of participants has been considered in turn. This concluding chapter reflects on similarities and differences in the responses of the different focus groups to issues relating to genetic testing and biobanking. The central focus of the chapter is the challenge of thinking across the cases – the LDS group, the rongoa group and the group of Māori lawyers. The goal is to make explicit the points of convergence and dissonance that have been indicated during the earlier discussion to highlight the notion that Māori resist homogeneity and are constantly negotiating living on the boundary of two worlds at the interface, Māori and Pakeha. This will be acknowledged by considering the ambivalence that each of the groups articulated.

2. Articulating Ambivalence

Representatives of all three knowledge communities/socialities who participated in this study had ambivalent responses to genetic testing and its implications for Māori. Generally genetic testing was viewed positively in terms of the benefits for future generations of providing information that could lead to prevention of genetic disorders. This is illustrated by the case of the Māori whanau considered in the opening section of this thesis. Knowledge about the genetic abnormality in this whanau created the possibility of women in the next generation using forms of genetic testing to avoid conceiving and birthing babies with this disorder. This still entails difficult personal and whanau decisions.

The positive responses of participants to genetic testing were sometimes consistent with the position adopted by Manuka Henare,[34] Associate Dean of Maori and Pacific Development at Auckland University's Business School. In response to negative comments about Māori participation in the National Geographic 'Genographic Project' he stated that: "More knowledge is always empowering … it is about a better understanding of ourselves and our past … the first question Māori ask of each other is where do you come from? Genetics [science] offers another way of finding the answer to that question" (Henare, 2005). However, many participants in the contact groups within this study did not always think that more knowledge was empowering.

Genetic testing was also approached with a certain amount of caution, scepticism and resistance. Many research participants were concerned about the way in which genetic medicine had developed in Aotearoa New Zealand without significant consultation with Māori at the whanau, hapu and iwi level. Members of these groups all used the concept of whakapapa as they responded to questions about genetic testing.

In many ways research participants across the different focus groups resisted engaging directly in talk about genetic testing. They often preferred to engage in talk about the frameworks that would shape their engagement with genetic testing. Where participants generally thought that the information pertaining to genetic testing was going to impinge on their lives then they would pay attention to it. In this regard, their conversation in the focus groups was most useful for access to

[34] Henare is a board member of ERMA (Environmental Risk Management Authority) and is regularly involved in discussion and debate about real fears some Māori have about genetic science.

information about the conceptual frameworks they utilised when confronting any issues, including genetic testing.

This relates to issues that others have raised about the problem of research agendas being set by researchers rather than by research participants. Lawyer and political activist, Moana Jackson (1998) endorses the importance of Māori researcher's engagement of Māori participants in research. He argues that Māori have and should set their own agendas rather than have agendas imposed upon them. In this research project the research agendas was set by the researchers who developed the overall Constructive Conversations Kōrero Whakaaetanga research project. In some respect at least, the LDS, rongoa and lawyers focus groups resisted that agenda and focused on things of most concern to them, whakapapa, mauri, kaitiaki, mana motuhake and the relevance of the Treaty of Waitangi for all of these.

The notion of whakapapa involves not only attention to descent but also to human/non human interactions and relationships (Roberts et al., 2004, Barlow, 1991). As indicated in Chapter 2, this attention to the relationships between people and things, parallels aspects of actor network theory that focuses on networks of connectedness between people, other animals, plants and other things like mountains, lakes and rivers (Latour, 1996). Lemke, endorses Latour's notion that "semioticially both human actors and nonhuman participants whether artefacts or naturalised constructs like bacteria were equally actants…the important fact is not that humans and nonhumans are treated symmetrically but that they are defined relationally as arguments or functions in the network, and not otherwise" (Lemke, 2000:108).

Participants were often concerned about the ways in which any change to the genetic make up of people, plants or animals would disrupt whakapapa - the complex relationship between all these aspects of existence.

3. Spiritual Beliefs and Genetic Testing

Spiritual and religious concerns featured were present to varying degrees in the talk of all three contact groups in this study. LDS members expressly stated that gospel teachings determined

their responses to genetic testing and whether they would use this technology themselves. While Te Ao Māori was relevant to their responses, their Mormon religious beliefs were more important in this instance than their cultural epistemological understandings. One of the participants said:

> I can live in both the Māori and the LDS gospel worldviews; I choose to adhere to my LDS principles if the Māori principles do not make sense to me… If anything is going to happen in my life, I am ruled by what I do in the church. I am ruled by that. I allow no Māori to overstep or over-ride that and I am so comfortable with that.
>
> (LDS, 2003:22-23)

The rongoa practitioners on the other hand, also held very dedicated spiritual beliefs that were fervently expressed in the ontological security of Te Ao Māori which has been argued to embody understandings of intergenerational connectedness. The rongoa practitioners, like the LDS deem it necessary to recognise the power of the kawai tipuna - the guardians over the entire universe and everything within in it. This is to ensure the wellness of not only the land, but people and animals including things animate or animate. For the rongoa practitioners' acknowledgement and respect of Tane Mahuta kaitiaki over the forests is paramount. Failure to perform rituals that acknowledged the realm of Tane Mahuta would result in misadventure which could lead to disastrous consequences.

The rongoa practitioners passionately emphasised the importance of rongoa and traditional spirituality, but also indicated that they had the capacity to access some forms of western medicine, for example, hip replacement, and dialysis. In that sense, they negotiate between knowledge systems while focusing on rongoa. The complexity of such negotiations has been illustrated in this thesis. Differently positioned Māori have embraced this complexity in distinctly various ways.

The lawyers who participated in this study were less inclined to draw explicitly on issues regarding spirituality. They expressed an implicit understanding of the interplay between the cosmological universe and the current social, economic climate which includes the discourse of the Treaty of Waitangi in their discussion of genetic testing. However, in contrast to the LDS and Rongoa groups, one law participant expressed his desire for active participation in genetic testing

that may improve individuals quality of life by suggesting that it was a "…a wairua issue …[which] we have to overcome" (Lawyers, 2004). This departure from the other group's articulation of their spiritual grounding highlights the ways in which Māori in different communities draw on different knowledges as they consider the implications of new technologies like genetic testing.

4. The Importance of Whakapapa

For LDS participants there was a strong connection between their spiritual beliefs and the importance of whakapapa. They articulated a strong sense of genealogy that links people back to their ancestry and forward towards future kin destined to obtain what they anticipated was 'celestial exaltation' or the highest degree of glory post mortality. LDS theology and their absolute faith in God means that LDS members focus on preparation for their after life by carrying out sacred ordinances that could link them to ancestors they have never met in a physical state.

LDS members articulated a strong sense of kaitiaki towards members of their family who have passed on without knowing the gospel or having been baptised and believe that it is only through baptism and repentance that people can enter into the Kingdom of Heaven. The work LDS members carry out for the dead is necessary if they and others are to connect as kin after death... For this reason the LDS participants tended to have little interest in genetic testing. It was seen as orientated to improvements in one's mortal life or that of one's children or grandchildren. Their attention is on life post mortality.

At the same time, issues relating to the new genetics do impinge on the lives of members of this group. One participant talked about living with a genetic condition in her family. She had brought her family together to inform them that they were potentially carriers of Fragile X. She considered that their Mormon faith would guide their decisions. Aroha had been contacted by geneticists and researchers prior to and after the interviews associated with this study and she considered that she was able to make informed choices about what she would want to participate in and what she would discard. She did not regret conceiving her children, but she was interested in knowing if she was a carrier for Fragile X. In her everyday life she negotiated the spaces

between her LDS beliefs and the knowledge available through genetic medicine about her children's condition.

Rongoa practitioners' talk about whakapapa was linked to their focus on the realm of Ranginui and Papatuanuku rather than the Kingdom of Heaven. Like the LDS, rongoa practitioners consider whakapapa to be a crucial element that connects humans and non-humans, including the physical environment. The health of the environment is seen to transcend the health and wealth of people. The rongoa practitioners articulate a discourse about a natural sate of being that can be disrupted by interference via medical interventions including contemporary human genetics, particularly interventions that involve any change in DNA. They are critical of interfering with the natural order of things, even when it could prolong life. As one participant in the group said: "one person dies in order for another to live" (Rongoa Māori, 2003). Genetic testing was associated with a desire to interfere with nature and fundamentally change whakapapa. In this respect it was inherently problematic.

The lawyers in this study focused on whakapapa in the context of tensions between individual and collective rights and responsibilities with respect to genetic testing and the storage of genetic information. They recognised that, while information about their own DNA may be of direct consequence to individuals, the desire to access this information and use it becomes problematic when whanau, hapu and iwi argue that the genetic testing of individuals has implications for the collectivities in which they are located and for whakapapa generally.

This illustrates the ways in which a core Māori concept like whakapapa was important across the different contact groups, but also considered in different ways within each group. For the lawyers this was a matter of negotiating individual and collective rights, but for the rongoa practitioners it was a matter of reflection on the relations between all animate and inanimate things. For LDS member's whakapapa could not be considered without attention to the spiritual understandings of genealogy that lies at the heart of Mormon belief.

5. Treaty of Waitangi and Genetic Testing

While the LDS group and the rongoa practitioners were more likely to draw explicitly on

spiritual beliefs and the significance of whakapapa in their responses, the group of lawyers were more likely to refer to the Treaty of Waitangi. For them the Treaty of Waitangi is a formal commitment to a partnership that acknowledges and supports the safety and protection of taonga which extends to genetic material. The lawyers argue that the treaty acknowledges and supports safety and projection of 'nga taonga tuku iho' - treasures passed down through the generations.

The rongoa practitioners used the Treaty of Waitangi relationship as a lever in their assertions of mana motuhake and agency with respect to traditional healing. The lawyers expressly considered the notion of mana motuhake could not be determined without first balancing the benefits and disadvantages of genetic testing. Parallel to this notion of mana motuhake is the social theoretical notion of "agency" as defined and conceptualised by Emirbayer and Mische (1998). This concept has also been mentioned in previous chapters and involves a focus on agency as an embedded process of social engagement, informed by the past, but also oriented toward the future. This accurately captures the ways in which the lawyers in this study view the treaty as a document with its roots in the past, but also a resource for achieving things in the future. Their agency with respect to genetic testing and the agency of Māori generally is conceptualised as involving strategic use of the Treaty.

The lawyers saw the treaty is a live document and as much part of New Zealand society today as it was in 1840. One of the lawyer participants argued:

> Māori need to be actively participating at the decision-making level, because that's how it should be. I think that's where it comes down to in terms of Treaty, jurisprudence, cultural evidence.
>
> (Lawyers, 2004)

The LDS participants also talked about the Treaty as a framework of good ethical practice on the part of geneticists and Māori. This was exemplified in the mutual understanding of Dr Robertson and the Māori whanau whose story began this thesis. LDS members were concerned about the use of genetic testing being driven by non-Māori and the need for Māori to ensure that this technology was used in ways that worked for Māori clients of the health system.

6. Commercialisation, geneticisation and the protection of genetic information

Participants overall were concerned about commercial involvement in biobanking. Their distrust was often linked to their understanding of colonial history, the tendency for knowledge to be commodified for profit and not for the benefit of all community members. They also saw their taonga and matauranga as exploited components of this same body of knowledge. They spoke about misappropriation of indigenous knowledge as an international phenomenon and an ongoing threat for Māori. The lawyers who participated commented critically on the mock biobank pamphlet in terms of the absence of Māori in the documentation and the lack of indication that those providing information for the biobank would in any way benefit from this participation. They saw the biobank as just serving the interests of academics, researchers and commercial biotechnology companies.

Many participants had concerns about the storage of genetic information. For all the participants in these groups DNA results were seen as part of whakapapa and treated as taonga, valued treasures that must be cared for and treated with respect. This meant that processes used by commercial testing laboratories and biobanks had to be governed by rigorous ethical procedures. Generally, genetic information was not seen as information solely about individuals, but as part of the whanau and whakapapa. (This is consistent with the understandings of geneticists). However, participants in this study had some different responses to the value of creating genetic data bases. For some participants, particularly rongoa practitioners and lawyers, genetic data bases were potentially problematic because they often involved individuals making decisions about being tested and recording their genetic history. However, members of the LDS group were more positive about the creation of genetic data bases.

LDS participants saw genetic data bases as a way of connecting the value given to descent within Mormon theology and the values attached to whakapapa among Māori. For LDS members this was linked to the possibility of eternal salvation for both the living and the dead. Mormons use genetic data bases to find the names of people who can potentially be baptised. For LDS participants in this study these acts of baptism are acts of agency in world. However, for Foucault these rituals of baptism might be seen as instances of ‘governmentality’ – acts that are experienced as agency, but are part of the way power operates through the ritualisation of

personal conduct and forms of self-government (Foucault, 1991: 87).

All three groups drew on Māori epistemologies to assert the notion that people were more than a conglomerate of genes, cells or carbon. They voiced concern about the possibility that increased genetic testing would lead to people being defined in terms of their DNA. In response to issues regarding the Genes Futures advertisement included in the stimulus material, and the potential to access genetic testing via the internet, participants reflected on questions around protection of information, confidentiality and what it means to know.

7. The Politics of Participation

Initially all three groups articulated their uneasiness about participating in the study because they felt they did not have enough prior knowledge about genetic testing. Satterfield et al (2005) cite on a written submission made by Māori lawyer Moana Jackson who addresses this issue in the following statement:

> The late Sir James Henare once said having to be reactive all the time is one of the hardest things for our people. It often limits how well we can address an issue because we are always rushing to meet someone else's timeframe or someone else's ideas of what is important. Every time we are asked to give a perspective we are already responding to something that has been decided or the main ideas already set in concrete. It is no wonder that we sometimes get confused…because neither the time nor the issue is our own. GM … is one such context… As a result our people have often been asked questions impossible to answer in timeframes impossible to keep.
>
> (Satterfield et al., 2005:110)

This statement highlights the challenges for many Māori of responding to public issues which are presented as demanding their attention. As they respond, they have to negotiate between diverse knowledge systems and consider the relevance of Te Ao Māori for issues like genetic testing. They do this in a context in which western knowledge systems, like medicine, are valued above systems of traditional indigenous knowledge like rongoa. In contrast, non-Māori are seldom challenged to step outside their knowledge frames and ways of life.

Concern about the value to participants of any research or data collection exercise was extended to criticism of the Constructive Conversations/Kōrero Whakaaetanga project. Members of the rongoa group in particular wanted reassurance about confidentiality and about Māori control of

the information produced and its analysis. They saw relationships between researchers and researched as political and were assertive about the need for clear and transparent information about the wider research project and its purpose. Discussion about these issues was necessary before they could be confident about the research process and the storage of the information they produced. Tensions in other transcripts have arisen regarding individuals versus the community.

8. Directions for the future? Questions and possibilities

This thesis began with several questions and concludes by posing further questions. How can different knowledge systems be acknowledged and valued in Aotearoa New Zealand? Can we create images of possibility and agendas for robust alternative futures? How can we access both conventional and unconventional wisdom and use them creatively? How can resilience be encouraged in the face of constant change? How can tikanga and matauranga develop interactively with western knowledge systems? How can we address the uncertainty of the future as we work towards asking better questions rather than achieving certainty about the answers?

My objective in this thesis has been to resist the tendency to homogenise Māori, while also demonstrating the ways in which Te Ao Māori shapes responses by differently positioned Māori to the challenges posed by new biotechnologies. I have demonstrated the ways in which three groups of Māori, located within overlapping, but also different knowledge communities or socialities, responded to the stimulus materials developed by the overall Constructive Conversations/Kōrero Whakaaetanga research team. I have also reviewed some of their critical responses to those materials, demonstrating that these participants were not 'respondents' but actively engaged with the questions and strategies used to facilitate their engagement with issues relating to genetic testing and biobanking.

Whilst these three groups shared common principles and values within Te Ao Māori, they also maintained their own mana motuhake and agency according to their practices within their specific areas of expertise. This agency shaped the way they responded to issues relating to genetic testing and biobanking.

Their overlapping and different responses highlight the importance of interactions with Māori in diverse locations when seeking knowledge about the implications for Māori of new developments in science and their potential applications in the field of human health. The connections and differences in their responses reinforce the need to activate a variety of different

Māori networks and involve researchers and facilitators with a multiplicity of connections and relationships of trust with community organisations. Researchers, scientists, and those involved in science and health policy development need to establish over time relationships with Māori with knowledge about the implications for their different communities of new technologies like genetic testing. Long-term connections and reconvened discussion groups that build on existing networks, and over time generate exchanges of knowledge, are the necessary basis for engagement by Māori and other citizens with new science, including human genetics.

My negotiation of the spaces between a western dominated social science discipline and Te Ao Māori has also been documented through this thesis. Like the research participants in this study, I have juggled different knowledge systems and occupied the uncomfortable boundaries between different ways of knowing and understanding. This negotiation of interfaces has been challenging, dis-comforting, at times paralysing, and is still ongoing. At the same time, these experiences have generated a commitment to embrace the difficulties of occupying a multiplicity of ways of knowing and being. In a country in which many knowledge systems, cultural values and ways of being are represented, negotiations across difference and the discomforts and insights they generate are pivotal as Aotearoa New Zealand responds to the uncertainties and possibilities available through new genetic science.

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Appendix I

Terminologies

Biotechnology: is technology that incorporates the use of biology and the components within. A broader definition has been provided by the New Zealand Independent Biotechnology Advisory Committee (IBAC) who extends the definition to include the application of 'scientific tools, which uses living things to solve problems and make products' (IBAC, June 2002). Genetic testing therefore is one aspect of biotechnology that shall be explored in the next section.

Commensurable: To be measured by a common standard

Epistemology: The branch of philosophy that studies the nature of knowledge its presuppositions and foundations and its extent and validity.

Genetic Engineering: involves the transference of genes horizontally between species that do not interbreed. It makes use of artificial vectors for replicating and transferring genes (Ho et al, 1999:7)[1].

Genetic Testing: is the technology of that determines the individual's genetic makeup such as the blueprint that is encoded in the cells of our bodies. The IBAC June 2002 report suggests there are various forms of medical uses of genetic testing. For the purposes of this thesis we shall only consider the three aspects of genetic testing that were utilised in the discussions with the three contact groups for this thesis. First there is the prenatal testing which is a test performed on an unborn baby to see whether or not the unborn baby carries any gene defects or has a disorder. The second genetic test is the predisposition or susceptibility test which is a test to see whether 'there is an increased likelihood of a particular disorder through genetic causes'. The third genetic test is bio banking which is the storage of genetic information onto a database that can be accessed by the organisers and potential government agencies.

Incommensurable: Impossible to measure or compare in value or size or excellence not having a common factor lacking a common quality on which to make a comparison.

Kaitiaki: The concept of kaitiaki utilised in this thesis has been defined by the participant's korero as a notion to protect to care and as an obligation of one's responsibility such as to take care of one's self, whanau and land. This is different from the idea of protection which is reflective of an individual title to property and land. Underpinning the notion of kaitiaki is the result of a sustainable environment that is dependent upon those who utilises the materials and resources accessible for human consumption and enjoyment.

[1] Ho, Mae Wan, Meyer Hartmut, Cummins, Joe (1999) The Biotechnology Bubble, in The GE Issue (ed) Cowperthwaite, Valerie Soil and Health: The GE Issue, July 1999

Knowledgeability: Wisdom as evidenced by the possession of knowledge

Ontology: The metaphysical study of the nature of being and existence. It is the study of being and knowing

Paradigm: A paradigm is an exemplar a particular scientific problem-solution that is accepted as successful and which becomes the basis for future work. Kuhns work suggests a paradigm is a resource to be used in the construction of understanding a scientific problem.

Sociality: The tendency to associate with others and to form social groups

Whakapapa: The principle of whakapapa is that body of knowledge that is bound within the intersections between people, the universe and nature.

Appendix II

Constructive Conversations Tools

STORY

"We would like to start by telling you a possible story, set ten years in the future. This is just to get us all thinking about where genetic testing might be going…

Imagine some events that do not happen at the moment, but might happen in say ten years from now (2013).

Your son (grandson/brother/friend – change depending on the group) and his partner have just had a baby.

The next day they are asked to sign a consent form so that a nurse can take some blood from their baby for a genetic profile.

Neither of the two new parents know about genetic profiling, so they ask the nurse to tell them what it is.

She says that this new technique is an extension of the routine screening that has been done on all babies born in New Zealand since the 1970s. She tells them that genetic profiling does more than the old 'heel prick' test.

The blood sample can be used to 'map' the baby's genes. This gene 'map' is stored electronically. It will become part of the baby's permanent medical record. This information can be used throughout the child's life to develop a personalised medical care programme that is specifically designed for the child

The new father's reaction is that this sounds like a good idea and that they should go for it.

If their baby has a genetic disorder (or a predisposition for certain diseases), the doctors will know about it early, and they may be able to offer advice and, if necessary, may be able to do something about it. He thinks it would be good to have this information so that it can be used if and when it is needed.

His partner is not so sure.

She is worried about what it means for the baby. For example, what if they find out that the child has a pre-disposition for diabetes, or ADHD, or Alzheimer's? How would the child feel about herself? Could this affect her employment prospects?

She is not sure if she wants her child's future to be mapped out right from the start – she thinks that she would rather the child's life just 'unfolded'.

She is concerned about who will have access to her child's genetic information. Will it be available to her doctor, to the early childhood centre or school? And in later life will it be accessed by employers, banks, and insurance companies?

Ask people to talk to their neighbour in the group about the new parents' dilemma. Whose view are you inclined to share – the mother's or the father's?

Critical Questions for Story

Some people say it would be a good idea to introduce genetic profiling for all new born babies. These people argue that:

Detecting a genetic mutation may provide an opportunity for early diagnosis of a disease, and prompt medical intervention and lifestyle changes.
Do you see this as a significant benefit of genetic testing for individuals/ whanau/ families and the community?

Genetic testing can give people the opportunity to make choices affecting their future health or that of their children. They can have more regular check ups and make life style changes that lessen the risk of disease.
Do you see this as a significant benefit of genetic testing?

Whether a genetic test is positive or negative, the results may relieve uncertainty and the stress of not knowing what will happen in the future. If the test is negative parents with a family history of a particular disorder can be confident that their children will not inherit it. If the test indicates that a disease will or may develop, people can make decisions about their lives in the light of that information.
Do you see this as a significant advantage of genetic testing? Why? Why not?

Some people say it would <u>not</u> be a good idea to introduce genetic profiling for all new born babies. These people argue that:

Babies cannot exercise informed consent; their parents are making decisions for them.
Should parents make this decision for their children? Why? Why not?

People already have a lot of information about lifestyle and health, but many of them do not change their diet, take more exercise or work less.
Do you think that access to genetic profiling will affect people's decisions about what they eat or drink or their hours of work?

It may be difficult to understand what it means to have a higher risk of developing a particular disease (e.g. diabetes, heart disease or cancer). Results of genetic tests can also sometimes be mistaken, causing unnecessary anxiety, or false reassurance.
Who should be responsible for talking to people about their genetic profile? What are the consequences for individuals and families of living with knowledge about genetic predispositions to various diseases?

Genetic profiling of newborns is costly, but it will save the health system money in the long term.
Do you agree? Why? Why not?

Some genetic tests are patented and this can make them expensive. Public health system resources are limited. Resources may need to be diverted from existing treatment programmes.
Is this a matter of concern? What are the resource issues associated with a genetic profiling programme?

People have a right to know as much about their own bodies as possible. Some people should not be denied the right to this information just because other people are wary about its implication.
Do you agree or disagree with this statement? Why?

Employers, banks, life insurance companies and health insurers could gain access to this information and discriminate against those who have a higher risk of developing certain diseases.
Is this a matter of concern? Should governments act to avoid discrimination on the basis of genetic information? What can they do?

Story: FAQ's

FAQ1

What exactly is the 'heel-prick' - or Guthrie - test (the test that is done now)?

Since the 1970s most new-born babies in New Zealand have been screened for seven congenital (inherited) disorders.

This is not actually genetic screening, but it indirectly tests for particular genetic disorders. The test involves taking a very small amount of blood from the sole of the baby's foot (which is why it is called the 'heel-prick' test).

- This blood is then 'spotted' onto a card made of special paper and allowed to dry.
- The card is called a Guthrie card.
- The cards are then sent to the National Testing Centre in Auckland for testing.
- The parents can ask for the card to be returned to them if they want it, but otherwise the cards are kept at the National Testing Centre.

Of the 60,000 or so babies born every year, only about 30–35 will have one of the conditions that are tested for. However, if these conditions are detected early (within a few days of the baby being born), the problems they cause can be greatly reduced by giving the baby a special diet or though various medical treatments.

FAQ2

What diseases does the Guthrie test pick up?

The Guthrie test is designed to detect seven disorders.
These are:

(i) Phenylketonuria (PKU)

(ii) Cystic Fibrosis

(iii) Congenital Adrenal Hyperplasia (CAH)

(iv) Galactosemia

(v) Hypothyroidism

(vi) Biotinidase deficiency

(vii) Maple Serum Urine Disease (MSUD)

FAQ3

Are Guthrie test records kept?

Yes.
Blood test records for all New Zealand babies born since the 1970s are kept at the National Testing Centre in Auckland (unless a parent has specifically requested that their baby's record be returned to them) in case there is later a need for a re-test.

FAQ4

How long are the records kept?

Indefinitely.
Because the National Testing Centre has been keeping all records collected since testing began in the 1970s, it now holds records on nearly all babies born in NZ for the last 30 years.

FAQ5
Does the NZ National Testing Centre allow anyone else to use these records?

When (if ever) would they allow a person's record to be released to someone else?

- When a mistake has been made in the testing and the sample needs to be re-tested at another laboratory
- To assist in pre-natal diagnosis in families that already know that they have a serious inherited disease (like cystic fibrosis)
- When requested by the police – for example when help is needed in identifying human remains
- When parents have requested that the sample be returned
- When there is a Court Order requiring the National Testing Centre to release the sample

i.e. they would only release the records in circumstances that will benefit the individual or family who are connected with the record.

The records are not used for research - or for any other purpose apart from the one for which they were collected.

FAQ 6

What exactly is neo-natal genetic profiling?

Genetic profiling of new-born babies involves making a 'map' of all the baby's genes (not just the ones associated with the seven diseases that are now tested for).

This 'map' will be stored electronically as part of that individual's permanent medical records.

FAQ 7

Are babies being tested in this way now?

It doesn't happen routinely yet, but the UK the government recently proposed that a national system be set up to develop genetic profiles of all new-born babies.* If this proposal is accepted, the system will be set up in the medium-term (about ten years from now) in the United Kingdom. Once established it will use these genetic profiles to develop personalised medical care programmes, tailored specifically to the needs of that individual, throughout their life.

The technology for doing this will soon be available.

This proposal has been controversial in the UK. Some clinicians argue that it will dramatically improve public health outcomes. However, the UK Human Genetics Commission has highlighted issues relating to privacy, informed consent, and genetic discrimination.

There is no programme like this in NZ, and no proposal to introduce one is currently being discussed here.

*See the recent White Paper written for the UK government: *Our Inheritance, Our Future: Realising the Potential of Genetics in the NHS* (June 2003) (p. 44-45).

Gene Futures Discussion

Materials needed

- Advertisement
- Critical Questions
- FAQ's

Process:

a) **Give out the Gene Futures advertisement** to each person (See p. 17)

b) **Group discussion:. *What do you see as the advantages of this direct to consumer service? What are the disadvantages?***

c) **Encourage people to talk to across circle**, not just through the facilitator

d) **Critical questions: Use as required**

e) **FAQS – use as required**

Gene Futures Advertisement – a mock advertisement created for this study

Gene Futures

Predictive genetic testing laboratory

Take control of your life

Take advantage of the latest genetic testing tools to help you understand and protect your health.

Get a **personal DNA profile** that will allow you to develop your own totally personalised health care plan.

Knowledge is Power

With your personal DNA profile, you'll receive information on how you can change your diet or your lifestyle to reduce your chances of developing diseases you may be susceptible to.

Fast

Your results will be available within 3 working days.

Private and hassle-free

You don't need to visit your doctor and the results don't go on your medical record.

Simple

You collect the DNA samples yourself (just a swab from inside your cheek),

Accurate

We offer the highest quality tests in the industry.

Affordable

We offer the lowest prices for the highest quality tests. Peace of mind is more affordable than ever.

Visit our website: www.genefutures.com and access our **fast and easy** internet service. Our website offers more information about DNA screening, including susceptibility tests to **Alcoholism**, **Depression**, **Attention Deficit**

Critical Questions for Gene Futures discussion

What do you see as the advantages of this direct to consumer service? What are the disadvantages?

The service provided does not include any counselling.
Should genetic-testing companies be permitted to advertise and supply directly to the consumer – without pre- or post-test counselling or discussions with clinicians? If counselling is important, who should provide it? Who should pay for it?

After the sample has been tested, it is kept, and becomes part of an international gene bank the company is setting up. The company plans to lease rights of access to the material to biotechnology companies for research. This research may lead to new tests or new medicines being developed and made available. Some of these tests may be patented. Public health systems will need to purchase these tests if they are to be available to the general public.
What do you think about this?

The Gene Futures company sends the tissue samples overseas for testing.
Is this a problem? Why?

Some people say the development of genetic profiling and genetic services has great potential to improve human health. They argue that companies should be given wide scope to do this research and development on a for-profit basis, much the same way as happens no for medicines.
What do you think about this? Why?

Some people say that the Gene Futures would have no way of knowing if a particular individual had actually agreed to have their samples sent, or even of knowing whether the sample actually belonged to the person named.
It is also difficult for the public to assess the quality of the tests done and the reliability of the information.
What do you think about this? Why? Should the quality of genetic-testing companies' procedures and results be monitored? How? Who should pay for this monitoring?

Some people are concerned that Gene Futures might sell the right to access the information in the data base to other organisations – such as banks (or other mortgage providers), life insurance companies, and health insurance providers.
How concerned would you be about that?

Some people say that a focus on genetic predispositions for certain diseases will reduce efforts to improve environmental and life style factors that affect our health.

What do you think about this?

FAQs Gene Futures

FAQ1

Why are some genetic tests so expensive?

Many genes were first sequenced by public sector laboratories. This information is freely available, and genetic tests based on these genes are relatively inexpensive. An example is the genetic test for Huntington's disease.

Other genes were sequenced, or 'acquired' and patented by private companies. Genetic tests based on these genes tend to be more expensive as tests can only be performed after buying a license from the company concerned. An example is the genetic test for breast cancer. This test can be performed only by Myriad Kinetics, or by its Australian partner, Genetic Technologies (GTC). Each test currently costs US$2500.

FAQ2

Why is NZ now being asked to pay more for genetic testing?

In 1990 a Kiwi researcher Malcolm Simons was awarded a patent for the 'junk' DNA in every plant and animal species. This includes 95% of all human DNA. 'Junk' DNA doesn't code for specific proteins, but does contain sequences which control genes, turning them on and off. This non-coding DNA is used in every genetic test.

Such a broad patent would not be issued today.

Dr Simons co-founded an Australian company Genetic Technologies (GTC) which holds this patent and is now trying to enforce it around the world. GTC has offered NZ public health institutions a national licence to continue offering genetic testing. For a one-off fee of NZ $10 million, plus an annual fee of $2 million. The Ministry of Health is concerned about the cost of this licence. It is currently considering whether to negotiate payment, or to challenge the patent.

FAQ 3

What is a patent?

A patent is a license granted to an inventor by government. It gives the inventor the legal right to stop anyone else from making, using or selling the invention without his or her permission for a certain period of time (usually 20 years). In return, the owner must make public a complete description of the invention. Those who support the patent system argue that much useful research and development would not happen without this incentive.

FAQ 4

What can be patented?

The patent law of most countries says that for something to be patentable it must:
Be new: the invention has never been made public before by anyone else.
Involve an inventive step: the invention would not have been obvious to someone else who had a good understanding and experience of the field.
Be "useful": the inventor has identified a practical use for the invention.
Patents can only be held by individuals or companies.

There is a difference between inventions and discoveries. Inventions are created by humans, whereas discoveries already exist in nature and are found by humans. Discoveries are not patentable.

The criteria for granting a patent in New Zealand are less strict than those applied in most other countries.

FAQ 5

What is the purpose of patents?

The main justification for the patent system is that patents allow inventors to make a profit on their inventions, and the possibility of making a profit provides an incentive for research and development.

FAQ 6

Is genetic material patentable?

The patenting of genes is the subject of major international debate. One issue is whether they can be considered inventions at all, rather than discoveries.
Arguments against the patentability of genetic material include:

- if a gene exists in nature, it is not "new"
- an inventor who isolates a gene does not invent anything
- sequencing a gene has become such a routine process that it cannot be regarded as inventive.

Arguments in favour of the patentability of genetic material include:

- an isolated and purified DNA molecule that has the same sequence as a naturally occurring gene is patentable because the DNA molecule does not exist in nature in an isolated and purified form. (This is how patent offices treat other chemical substances that occur in nature.)

FAQ7

What is the purpose of genetic counselling?

These notes provide background material on genetic testing for diseases and health conditions, and not for gender or homosexuality and other characteristics some people claim are genetically determined.

Pre-test counselling:

The purpose of pre-test counselling is to ensure that the person understands what the test can and cannot tell them, as well as what will become of the genetic material they submit; and to invite those tested to reflect on how they might feel about a positive or negative test result.

The meaning of genetic test results is easily misunderstood. Tests can, if done well, tell accurately whether a person *has* a particular gene. But in most cases there is little knowledge about what it *means* to have the gene. That is, many people with the gene will not get the disease; and many people without the gene will get the disease. In most cases we do not know whether having the gene means you have a 50% or 1% chance of getting the disease later in life. This is because most "genetic diseases" are actually caused, at least in part, by environment (e.g., air pollution) and lifestyle (e.g., type of diet), as well as a number of different genes.

Post-test counselling:

The purpose of post-test counselling is to ensure that the person understands the meaning of the test results. It also seeks to ensure that people are made aware of prevention and treatment options, if there are any.

Post-test counselling is intended to supply answers to such questions as:
If a person has the gene, what does this mean about their risk of getting the disease? How much is known about this risk and whether it depends on other factors? Is there anything they can do to reduce the risk? Are they likely to pass on the gene to their children? If they do not have the gene, does this mean they cannot get the disease? (For most "genetic diseases", people without the relevant gene can still get the disease.)

BioBank discussion

Materials needed

- BioBank Pamphlet (see Biobank pamphlet file available on the same webpage as this Take Out Kit for researchers)
- Critical Questions
- FAQ's

a) **Give out BioBank pamphlet**

b) **Group discussion**: Imagine you or an older relative have been asked by your doctor to contribute to the BioBank project. ***How would you respond to this request? What advice would you give to your relative?***

c) **Critical questions**: Use as required

d) **FAQs**: refer to Gene Futures FAQs

Critical questions for BioBank discussion

Imagine you or an older relative have been asked by your doctor to contribute to the BioBank project.

How would you respond to this request? What advice would you give to your relative?

Do you think that non-profit research organisations (for example the Cancer Society or the Heart Foundation) should have access to the data that is 'deposited' in the BioBank?

Why? Why not?

Do you think that commercial biotechnology companies should have access to the BioBank data?

Why? Why not?

Some people say that one effect of the development of genetic testing has been to over-emphasise our genes as the source of 'who we are'.

Do you think the BioBank project will contribute to this?
What do you think about this?

Appendix III

Information sheet

Tēnā koe,

My name is Trina Taupo and I am currently an M.A. student in the Sociology Department at te whare wananga o Waitaha, the University of Canterbury. I would like to invite you to participate in a major new research project headed by: *Kōrero Whakaaetanga-Constructive Conversations: Biotechnologies, dialogue and informed decision-making.*

This will involve talking to other people about genetic testing. It will take two to three hours of your time. If you agree, you will be asked to meet with the same group of people again in 5-6 months, to talk in greater depth about this issue.

Read further to find out more about this project…

This project is designed to create opportunities for many people to contribute to a national conversation about the social, ethical, spiritual or practical issues associated with genetic testing. It will involve contact groups, interviews and day-long workshops which will bring together a range of different people to talk about the social implications of these new health practices. Throughout the five years of the research, our project website will provide information, updates, and further opportunities for participants to discuss genetic testing, and other new biotechnologies, with other members of their contact group. Members of contact groups will have access to all information and other resources provided to other project participants. This website is still under construction, but next month you will be able to access it at: http://www.conversations.canterbury.ac.nz

What will happen in the contact groups?

About eight to ten people will meet in a comfortable room, at a time that suits them. The meeting will last approximately two and a half hours. This includes a period at the beginning for refreshments and informal chat, and a period at the end, in which we will appreciate any feedback you wish to offer us. The discussion about genetic testing will take about one and a half hours.

The meetings will start with a welcome from the researchers and an opportunity for everyone to say a bit about themselves. We will also discuss how to make sure the conversation is supportive and constructive for all participants; we believe that processes derived from those used at Māori Hui can help us achieve that. We will then introduce a possible future for the provision of genetic testing services in New Zealand. This is based on trends which are already apparent overseas. The group will be asked to discuss this scenario. Towards the end of the session, we will ask you to share with us any questions the discussion has raised for you, or issues you would like

to discuss further in the second contact group meeting. This discussion will be audio-taped and transcribed.

We will also ask you to fill out a short questionnaire, and will also ask for feedback from you about the contact group meeting. The questionnaires are anonymous. We will code them so we are able to link information on the questionnaires with particular voices on the transcript; these will also be coded, and thus are anonymous. However, we will not link questionnaires with names or contact details. Our processes ensure that this information is kept entirely separate.

If you agree to participate, we would very much like you to attend a second contact group meeting in about five months time. Before this second meeting, you will receive information about genetic testing which is relevant to questions raised in the first meeting you attended. We hope that this second discussion will involve more in-depth discussion. If you wish to attend one of the workshops we are planning for the second year of the project, we will make that possible.

If you wish to withdraw from the group, or from more long-term participation in the project, you are free to do so at any time. Simply tell the project manager (contact details below) that you want to withdraw. If you decide to withdraw, we will not use any of the information you have provided. Your privacy is important to us, and any information you do provide is strictly confidential. Your contact details will be kept in a locked cabinet in our research office. These will be held separately from any record of the contact group conversation. This information will also be kept in a locked cabinet, or on a password protected computer.

If you would like to participate in this study or receive more information about it, please contact our project manager:

Dr. Lesley MacGibbon
Social Science Research Centre
University of Canterbury
Private Bag 4800
Christchurch

Telephone: (03) 364-2340
email: conversations@canterbury.ac.nz

Constructive Conversations is an independent research project funded by the NZ Foundation for Research, Science and Technology. The project team includes social scientists, biological scientists and ethicists at four universities and at the New Zealand Council for Educational Research.

Principal investigator: Rosemary Du Plessis, Dept of Sociology and Anthropology; University of Canterbury. Email: Rosemary.Duplessis@canterbury.ac.nz

Coordinator for the contact group methodology: Dr. Anne Scott; Dept. of Sociology and Anthropology; University of Canterbury. Email: A.Scott@canterbury.ac.nz

Consent form

_____

Constructive Conversations: Biotechnologies, Dialogue, and Informed Decision-Making

I have read and understood the description of the above named project. On this basis, I agree to participate in the project.

I understand that the information I provide will be used to provide reports and publications relating to genetic testing. However, these contributions will be strictly anonymous. I may at any time withdraw from this project, including withdrawal of any information I have provided. I understand that my privacy will be carefully protected, and that any personal data relating to me will be kept in a locked and secure location.

I am, provisionally, also willing to contribute to the process during the second stage of the project methodology, in approximately 5-6 months time. I understand that I am perfectly free to withdraw at that stage, if I do not want to participate in a second contact group.

NAME (Please print):_____

Signature:_____

Date: _____

Contact address, email and/or phone number (for arranging 2nd contact group):

Appendix IV

Return of Transcripts

17 June 2004

Address

Tēnā koe Name,

Ko Trina Taupo tenei ka nui te mihi nunui ki a koe mo to awhi mo to manaaki ki taku maha mahi mo genetic testing. He mihi aroha ki a koe mo to korero ki ahau tena koe.

I would like to take this opportunity to express my deep appreciation for your contribution towards my research study on local community's viewpoints regarding genetic testing.

I express my apologies for the delay in returning the transcript to you as promised, as I have been ill for the last six months and have endured a long and slow recovery. I am still on the mend at this time, but am aware that there are certain obligations I need to fulfil before I continue my research journey. My thesis has been suspended since February 2004, but I intend to recommence my thesis in the beginning of July and aim to complete the thesis in December.

I have enclosed a copy of the transcript undertaken at the focus group interview in December of last year and would appreciate, if you could check the transcript to ensure that any comments made in the interview are correct and that the content enclosed can be disclosed as part of my research, whilst remaining anonymous. When you have completed your comments (if any) could you please return the transcript at your earliest convenience in the self-addressed envelope.

If you have an email address please feel free to contact me kpt17@student.canterbury.ac.nz

Once again, thank you for your support in my endeavour to seek a way to encourage the voices of local community groups to be heard within areas of policy and decision-making on genetic testing.

I look forward to hearing from you.

naku noa

Trina Taupo

Appendix V

Constructive Conversations
Kōrero Whakaaetanga
Social Science Research Centre
Dept of Sociology and Anthropology
University of Canterbury

Contact Letter

19 November 2003

Kia ora (Name of Contact Person),

Please find enclosed two sheets.

The first is entitled: Constructive Conversations/Korero Whakaaetanga: Talking about genetic testing.

This is basically a general background on whom we are and why we are interested in talking about genetic testing with you and (Name of the organisation).

The second is entitled: Information and Consent form.
This basically outlines the process that will be utilised in conducting the research discussion. Attached to the info sheet is the consent sheet that I need filled out prior to our arrival, otherwise I'll just bring more when I come up to the hui.
The consent form is to allow us to audio-tape the interview.

If you have any problems please let me know.

As per our discussion this morning, I would really appreciate it if an interview could be scheduled with Māori members of the LDS church around the first weekend of December. Please let me know if this is suitable or if I need to change the dates.

Thank you for your support

Naku noa na

Trina Taupo

Private Bag 4800 Christchurch. Ph 3643240 Email: lesley.macgibbon@canterbury.ac.nz

Appendix VI

Contextual Questions

LDS

Who are you?
What motivated you to come today?
Do you feel there is conflict between tikanga, values and principles between Māori understanding and LDS teachings? If so why, if not why not?

Rongoa Māori

How long has your organization been practicing rongoa Māori?
Is your organization contracted to the Ministry of Health and the local District Health Board and any other agencies?
When did your organization begin and how, what is the mission statement?
How many rongoa clinics are there that you know of in the country and how many clinics like this are there in your area?
How long have each of you practiced as kaimahi/ workers?
What are the services your organization provides?
Does the community at large participate in any of the services you provide?

Lawyers

How long have you been practicing law?
What motivated you to this vocation?

Appendix VII

Letter Received from LDS participant

Friday 5th December 2003 – This letter was received Friday night prior to the research hui with Māori members of the LDS group by a teacher at a local wharekura who had this to share:

Dear Trina,

Sorry, I can't make this meeting but here are some general thoughts I'd like to include in your discussion regarding genetics, the church and Te Ao Māori.

Māori – We believe in whanau mo ake tonu atu. We believe in God (Io), we know he created us in his image. We believe that there were Gods who helped create this wonderful world. We revere what deity created. We also know that prophets lived and guided us from the beginning. We also know through the teachings of our tupuna that we are chosen and prestigious people who, through our diligence and obedience to the laws of a Heavenly Father including honouring and looking after our bodies we will inherit once more after leaving our mortal existence regain a beautiful exalted body. However, we will not enjoy this blessing if we choose to allow science to desecrate this same body. We do not support cloning, abortion, and any other form of "Man-directed operation"

Church – Again, like Māori the church also teaches us the sacredness of the body. It is also important for us to know who we are. We are the children of a Heavenly Father. We are created in his image. We believe that mortality is only a stage of ling and that we can prepare for an eternal and exalted life after we die and are resurrected. The teachings we accept as gospel and teachings speak of respecting, honouring and caring for our bodies. We also learn of the sanctity of the body. The commandment given to Adam and Eve, our first parents "to multiply and replenish" the earth is still relevant to us today. Abortion is no sectional. Because of the faith that individual members have of a living God an eternal Heavenly Father, there is no doubt that the church membership accept the teachings of our Lord, and do not accept the "man-oriented" ideas which are contrary to the teachings our Heavenly Father".

Appendix VIII

24 November 2003

Kia ora Brother Walmsley,

My name is Trina Taupo and I am an ex pupil of CCNZ. I am currently undertaking a Masters programme at the University of Canterbury in the School of Sociology and Anthropology.

Presently, I am in the process of organising a focus group with members from Hamilton with the help of my mum, Melame Taupo. I am interested in finding out what LDS members think about the impacts and effects of genetic testing particularly with regard to the strong cultural, spiritual understandings that they may bring to any engagement with science and technology.

There will be a maximum number of 8 participants and 2 facilitators so 10 people in total. All the participants are members in Hamilton and I'm a member but reside in Christchurch and my co-facilitator is Dr Fiona Cram from Auckland.
The date I have set for the hui is Saturday December the 6th at 9am and will conclude after 2 ½ hours discussion.

At the moment I am trying to secure a venue and would love to have the focus group at college, as I think it the most appropriate place to have discussions about such a controversial topic.

I thank you for your time in considering this request and am happy to answer any questions you may have.

Email: kpt17@student.canterbury.ac.nz or
Postal address: 15 Tintern Avenue, Avonhead, Christchurch
Phone: 021-2659385

Naaku noa

Trina Taupo